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THE ALMSHOUSE REVISITED:

HEAVY USERS OF EMERGENCY SERVICES

by

RUTH E. MALONE

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

NURSING

in the

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of the

UNIVERSITY OF CALIFORNIA

San Francisco

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HEAVY USERS OF EMERGENCY SERVICES

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by

Ruth E. Malone

Deep within every human being there still lives the anxiety over the possibility of being alone in the world, forgotten by God, overlooked by the millions and millions in this enormous household.

Kierkegaard (1980), p. xiii

To my parents, Wayne & Orva B. Malone,
from whom I learned first, to trust;
next, to care,
and then to question

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It is astonishing that the illusion is still maintained, in the academy, that the dissertation is written by a single individual. The image of the solitary student, alone late at night in library or laboratory, is true enough: I spent untold hours before my computer in the preparation of this work. But I did not write it alone. Yes, I wrestled with the often-obdurate language; yes, I typed the words and revised and revised and revised--but I was never entirely alone. There with me were untold other persons who have helped me along the way, who believed in me and in the possibility of this work; who encouraged me before the work was even conceived; who listened to me, cleaned house for me, put up with me, and cared for me when I despaired, and who reviewed many drafts of earlier versions. Where I have succeeded, credit is owed them; where I have faltered, I take full responsibility.

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This work was brought forth by those who helped me in many ways. First, I must thank my parents, whose love and care nurtured my possibilities and shaped who I am. My father, the oldest son of a poor small farmer, was the first college graduate in his

family. He earned a baccalaureate degree in electrical engineering and set out to the northwest to explore a world he had dreamed about as a boy. As an adult, he pursued a wide range of interests in the world around him, studying history, archeology, geology, astronomy, and following current events with keen interest, observing the stream of public life with a quiet wit and wisdom. My mother was an outstanding student through eighth grade and then was told by her father, a Missouri sharecropper, that "girls didn't need" more education than that. She went on to educate herself on her own, a process that continued all her life. She surrounded herself with books; our regular visits to libraries and bookstores were always cause for celebration as we found wonderful, new-to-us volumes. She had worked as a practical nurse before marrying, in a county cancer hospital where she cared for the poorest patients after their disfiguring surgeries for head and neck cancer. Her stories of her hospital work, which remained vivid and meaningful for her even though she never again worked in nursing, no doubt influenced my choice of career and my concern for those who suffer. My great regret is that my mother did not live to see the completion of this dissertation; she died just as I began this work. But there is no doubt that my parents' shared passion for learning and exploration shaped my own.

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Finally, I must thank all the participants in this study who so generously, so honestly, and so hopefully shared their stories, their time, and their experiences with me. It was their voices that brought this work into being, and I tried to get out of the way.

THE ALMSHOUSE REVISITED:
HEAVY USERS OF EMERGENCY SERVICES

Ruth E. Malone

ABSTRACT

Hospital emergency departments (EDs) provide a "window" on cultural definitions of social and medical issues as problems because EDs serve as society's "safety nets." The problem of heavy use of ED services nests within a complex of larger problems, including lack of access, inadequate social services, and community breakdown. This study's objective was to improve understanding of the phenomenon of heavy ED use by describing the contexts within which such use occurs and exploring the meanings of such use to heavy ED users.

People who use EDs most frequently--those "caught" in the "safety net"--are the poorest in our society: the mentally ill, those with chronic, disabling physical conditions, substance use problems, and/or compromised social support. Interventions to reduce their use of services have not proven consistently effective; this interpretive ethnographic study suggests several possible reasons why, including the irrelevancy of economic disincentives to desperately poor persons, safety concerns, and the relationships these patients often have with hospitals as institutions that represent public caring and "help."

Data sources included participant observation in two urban hospital EDs, conducted over a total of twelve months; in-depth interviews with 46 patients identified as frequent visitors; medical records review, and group interviews with ED care providers. Seventy percent of the patients were homeless or on public assistance. The majority had chronic medical problems.

Findings clustered into four interrelated themes: legitimacy, helplessness and heroism, recognition, and community. Within each, common concerns of both patients and clinicians revealed the way structural, ideological and economic constraints on caring practices contributed to moral, social, and physical distress and, at times, to overuse of EDs.

Deriving from these themes, four social trends emerged as noteworthy: the tension between the simultaneous processes of medicalization and demedicalization; the struggle for dominance between biomedical and market perspectives; widening cultural fears of dependency and of one another; and increasing difficulty in finding public space for care. These point to the urgent need for work in practice, policy, education and research aimed at resisting the tendency to commodify all aspects of public life.

Patricia Benner

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CHAPTER ONE

HEAVY USERS OF EMERGENCY SERVICES: BACKGROUND AND REVIEW OF THE LITERATURE[1]

Introduction

More than twenty-five years ago, a group of Yale University researchers called the hospital emergency department (ED) "a window to the unsolved problems of health service for a growing and mobile population" (Weinerman, Ratner, Robbins, & Lavenhar, 1966, p. 1055). In 1980, the United States National Research Council's Committee on Emergency Medical Systems expressed concern that the emergency department might be "a victim of conflicting interests" (National Research Council, 1980, p. 2). In 1992, a cover story of Hospitals proclaimed that United States hospital emergency departments, society's "sagging safety net," were "on the brink of crisis" (American Hospital Association, 1992a, p. 26).

The study described herein sought to glimpse the view from the inside of the "safety net" by paying attention to the voices of patients who use EDs most and the ED clinicians who care for them. This chapter reviews the literature on heavy ED use in order to sketch out how hospital emergency departments remain today a "window" on wider social issues; how the definition of those issues as problems by different key players in health care is based on different and often conflicting premises; and how the failure to achieve a relatively uniform social construction of the problem suggests the need for research aimed at increasing our understanding of the structural, ideological, and ethical parameters of the problem. The literature potentially related to this "problem" is vast and multidisciplinary; this chapter focuses on sampling work which addresses heavy ED users

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and which is representative of a particular theoretical matrix for social construction of this "problem." The literature review is further extended in Chapter Two, which focuses on economic aspects.

The Larger Context

Development of EDs.

In the 1950s and even as late as the 1970s in some nonurban areas, EDs were little more than "rooms"--holding areas for patients who were being admitted. Doctors still made "house calls" for emergency and after-hours situations, and EDs provided only minimal first aid; often these areas were not staffed full-time or were staffed with a single nurse who notified an on-call physician if a patient's condition warranted immediate medical care. Ambulance services, where they existed, were often run by undertakers, only about half of whom had any first aid training (Emergency Medical Services, 1972).

Emergency Services Specialization and Public Awareness.

With the development of increasing specialization in health care and other arenas, emergency medicine and emergency nursing emerged as specialties with their own standards of practice, professional organizations, journals, and certifications. New technology was developed for emergency treatment of illnesses and injuries. Emergency medical services (EMS) systems were established. In the United States, these were created with funding and mandated standards from the Highway Safety Act of 1966 (P. L. 89-564) and the EMS Systems Act of 1973 (P. L. 93-154). The media, attracted by the drama inherent in emergency services work, helped publicize the need for improvements and the establishment of such public programs as 911 services and widespread cardiopulmonary resuscitation (CPR) training for the lay public (Emergency Medical Services, 1972; Safar, Benson, Esposito, Grenvik, & Sands, 1974). In recent years, a proliferation of "real life" emergency television shows has drawn increased public attention to the emergency services setting.

ED Utilization.

Concomitantly, the utilization of emergency services has risen dramatically (Davidson, 1979). From 1954-1970, there was a 308% increase in the number of visits to EDs of community hospitals (American Hospital Association, 1972). Between 1970 and 1979, ED visits increased by 97%, while hospital inpatient visits increased by only 17% (Gardocki, 1983). In the first six months of 1980, according to estimates from the National Medical Care Utilization and Expenditure Survey, 11% of the United States population visited an ED (Chyba, 1983). In 1970, there were 120.2 ED visits per 1000 population; by 1979, the rate had increased to 218.8 visits per thousand (Gardocki, 1983). During the second half of the 1980s, hospital outpatient visits, including ED visits, increased at an annual rate of 6.1%, compared with a rate of increase of 2.2% for the first half of the decade; in 1990, there were 92 million ED visits in the United States (American Hospital Association, 1992; Donham, Letsch, Maple, Singer, & Cowan, 1991). The ED has become a primary care site for many poor and uninsured patients; growth in ED utilization is concentrated among Medicaid/ Medicare patients and the uninsured (GAO, 1993a). Sixteen percent of a sample of patients at a public hospital identified the ED as their regular source of care (Baker, Stevens, & Brook, 1994).

Heavy Users of ED Services

Definitions of Heavy ED Use.

A small group of ED patients accounts for a large percentage of the visits and costs of services provided in emergency departments (Berki, et al., 1985; Zook & Moore, 1980). Definitions of heavy use in the literature vary from as many as 20 or more ambulatory care visits per year, not limited to ED visits (Berki, et al., 1985) to as few as three visits per year (Schneider & Dove, 1983), but a majority of studies that focus specifically on this group and setting use a definition of four or more visits per 12-15 months (Andren, 1988; Andren & Rosenqvist, 1985, 1987a; Hansagi, Allebeck, & Edhag, 1989; Hansagi, Allebeck, Edhag, & Magnusson, 1990; Hansagi, Edhag, & Allebeck, 1991; Hansagi, Norell, & Magnusson, 1985). One study found that 11% of ED patients had four or more ED visits in a 15-month period and accounted for 32% of the total number of ED visits (Hansagi, Edhag, & Allebeck, 1991). Using a broader definition of three visits per year, other researchers found that 23% of the patients presenting to an ED account for as much as 73% of the visits (Schneider & Dove, 1983).

At San Francisco General Hospital, for example, which is part of a well-developed public health system of primary care clinics, homeless shelters, and other services, the 2683 patients who visited the ED four or more times in one year accounted for fully 25% of the 71,468 visits during one year. Patients who visited the ED ten or more times during the year accounted for 8% of all visits and averaged 15 visits per year. The "top 200" patients visited the ED between 13-59 times apiece, far above the overall average of 1.7 visits per year for ED patients at this publicly-owned facility (Wachsmuth, Gelb, & Scaletta, 1993).

Characteristics of Heavy ED Users as a Group.

These "heavy users" of emergency services comprise a population whose ranks are disproportionately filled with the socially marginalized: the mentally ill, the drug- and alcohol-dependent, the poor, minorities, and those with unstable family situations or without social support (Andren, 1988; Andren & Rosenqvist, 1985, 1987a; Berki et al., 1985; Bohland, 1984; Dicker & Sunshine, 1987; Hu, 1992; Padgett & Struening, 1991; Purdie, Honigman, & Rosen, 1981; Ullman, Block, & Stratmann, 1975). The majority of heavy ED users in one public hospital study were found to be unemployed, homeless, and in need of substance abuse or alcohol treatment (Okin & Boccelari, 1994).

They are considered problematic for various reasons: in an era when EDs are experiencing "gridlock" (a situation of departmental overload) due to unavailability of inpatient beds and their relative inability to turn away patients (GAO, 1993a; Gallagher &

Lynn, 1990; Koska, 1989), this population is felt to contribute significantly to overcrowding and extended waiting times; this population accounts for a portion of expenditures much larger than their proportion of the general ED population; and emergency care is expensive and follow-up is limited or impossible, so the ED is considered an inappropriate site for primary health care delivery. Finally, and perhaps most significantly for this analysis, the "heavy users" tend to come from socially stigmatized groups and often have multiple chronic health problems not readily treatable on an emergency basis (Mannon, 1976).

Theoretical Organization of this Review

Social Constructionism as a Tool for Reviewing the Literature[2]

The social constructionist view posits that the definitions of a problem are constitutive of that problem (Blumer, 1971; Kitsuse & Spector, 1973; Schneider, 1985). Linder, in a cogent analysis of the social construction of the injury problem, suggests that there are three types of premises involved in constructions of social problems: 1) premises about the causal agents and mechanisms ; 2) premises about the level and units of analysis appropriate to studying the problem and targeting treatment; and 3) premises about the preferred forms of intervention (Linder, 1987). These sets of premises, Linder proposes, are "nested" and the latter two depend upon the first. Utilizing Linder's framework for exploring the tacit assumptions underlying differing views of a problem, I propose to review the literature relating to the "problem" of heavy users of ED services in the United States from four perspectives, which I will call the biomedical perspective, the public health and welfare perspective, the legal perspective, and the market perspective.

I add the caveats that these perspectives are not *necessarily* linked to particular groups of players, although they may be more deeply embedded in the activities of certain

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[2] For a fuller discussion of social constructionism as it informs the methodology of this study, see Chapter Four: Methodology.

professional groups; some individuals may experience significant convergence between them; and these perspectives are not meant to be all-inclusive. Nor are these categories as clearly delimited as this analysis might suggest. My intention is, rather than attempting to exhaust the possible interpretations of this phenomenon (or the potentially related literature, which, as noted above, is immense), to try to uncover some of the philosophical conflicts in its social definition which may inhibit effective social resolution strategies.

Intersections with Phenomenology[3]

Finally, I would emphasize--diverging somewhat from Linder-- that I do not mean to imply by naming these perspectives that they are always--or even usually--overt "belief systems" or intentional choices. Rather, "I have in mind flexible, undefined 'taken-for-granteds' which allow practices to make sense" (Gordon, 1988, p. 23). Thus I seek to integrate the social constructionist idea that problems are defined and created by our understandings of them with the phenomenological notion that such understandings are primarily experiential rather than cognitive. The work of Dreyfus (1991A, 1991b), explicating Heidegger, is useful in understanding this distinction; also see Benner & Wrubel (1989). In the Heideggerian phenomenological perspective, I am both constrained by and enabled to "make sense" of things by my own "background understandings," about which I can never be fully explicit, since I can never actually be privy to an "objective" stance. The premises I will attempt to discuss, then, first assume overt dimensions in the form of common understandings and accepted practices.

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[3] For further discussion of the philosophical assumptions of phenomenology and the phenomenological method that informs this study, see Chapters Three and Four.

Theoretical Premises in the Literature

The Biomedical Premise

What I will call the biomedical understanding has drawn heavy criticism from many quarters in recent years, but its "tenacious assumptions" are both subtle and ubiquitous even outside the medical arena. Within health care, as Gordon notes,

> ostensible reforms--such as psychosomatic medicine, holistic health, the expanded 'biopsychosocial' model..., 'bioethics,' and the patient autonomy movement--often retain the basic values and assumptions of biomedicine and unwittingly perpetuate the 'status quo' (1988, p. 20-21).

Implicit to this understanding are Cartesian notions of the person as rational, autonomous, self-determining, and self- and other-objectifying.

During the twentieth century, and most obviously during the past two decades, the liberal paternalism of Western medicine has gradually yielded to an assortment of self-care ideologies emphasizing individual responsibility, but the basic biomedical understanding of what it means to be a person has remained largely unchanged. Kirmayer (1988) describes this concept of person:

> The Western concept of the person is of a relational agent, which occupies a space within the body, which itself dwells within the social world...the value of the person lies in his strength or will which is defined always in opposition to the other--whether that other be society, nature, or the body itself (p.79).

Mannon (1976) demonstrated how certain groups of patients (many of the same groups who are today identified as "heavy users") are defined as "problem patients" in the ED setting because their care needs are not compatible with the unit's primary objectives (also see Grief & Elliott, 1994; Jeffery, 1979; Kelly & May, 1982; Liggins, 1993; Roth, 1994; Wright & Morgan, 1990). To the degree that heavy users of emergency services are assumed to be entirely rational and autonomous beings, they are, in the biomedical perspective, themselves the causal agents of the problem because of their perceived "inappropriate" utilization of the ED; their presence is itself the mechanism by which overcrowding and associated pressures occur, and these are understood to constitute the "problem."

Because of their status as "problem patients," heavy users have been of great interest to clinical researchers, who have tended to focus on their group characteristics or on testing interventions aimed at individual patients in an attempt to get them to decrease their "inappropriate" ED utilization (Derlet & Nishio, 1990; Derlet, Nishio, Cole, & Silva, 1991; Hansagi, Allebeck, & Edhag, 1989; Jacoby & Jones, 1982). Yet this emphasis on reducing ED utilization, which may tend to blur distinctions between the overlapping categories of heavy users and "inappropriate" (nonemergency) users (both "problem" populations), obscures the fact that the population of heavy users has been shown to be at higher risk for death, (particularly by suicide), sicker or more likely to be significantly disabled or chronically ill, and more likely to need to be hospitalized as a result of the ED visit (Hansagi, Allebeck, Edhag, & Magnusson, 1990; Hansagi, Edhag, & Allebeck, 1991; Schneider & Dove, 1983). In contrast with this population, the "minor illness" population using the ED does not come disproportionately from poor or minority groups and does not appear to have a high rate of chronic illness (Shesser, Kirsch, Smith, & Hirsch, 1991).

In 1972, the American Hospital Association (AHA) defined an emergency as

> any condition that--in the opinion of the patient, his family, or whoever assumes the responsibility of bringing the patient to the hospital--requires immediate medical attention. This condition continues until a determination has been made by a health care professional that the patient's life or well-being is not threatened (American Hospital Association, 1972, p. 7).

This very subjectivist definition was contrasted with that of the "true" emergency, which was "any condition *clinically determined* to require *immediate* medical care" (p.7, emphasis in original text). The latter, implicitly, was "objectively" determined by health care providers. However, by 1982, the American College of Emergency Physicians (ACEP) felt the need to adopt guidelines defining "appropriate" visits to EDs:

> We feel that a patient has made an appropriate visit to an emergency department when: An unforeseen condition of a pathophysiological or psychological nature develops which a prudent lay person, possessing an average knowledge of health and medicine, would judge to require urgent and unscheduled medical attention most likely available, *after consideration of possible alternatives*, in a hospital emergency department (ACEP, 1985, p. 47, my emphasis).

The "blame the victim" connotations of the individual responsibility perspective are set aside for those who meet the definitions of "true" emergencies, since they are assumed to have met with circumstances outside their control and since they present providers with work well-suited to the providers' setting and orientation. But "inappropriate" users are heavily censured, particularly if they happen to be poor/Medicaid patients: one Texas physician wrote a letter to his state medical society journal proposing a punitive reduction in public assistance checks for non-emergency use of the ED (Wehmer, 1992). Patients who fail to carry out recommendations for care of themselves at home or for making follow-up appointments may be "diagnosed" as "noncompliant." Heavy users or non-emergency users, particularly if they are receiving public assistance, are called "abusers" of the care system. The irony of this shift in perspective is nicely summarized by one critical observer:

> Previously, the poor were blamed for not using medical services enough, for relying too much on their own resources, and for undue suspicion of modern medicine. Now they are blamed for relying too much on admittedly ineffective medical services and not enough on their own resources (Crawford, 1977, p. 670).

One study initiated a system of triage in which patients presenting to the ED were simply refused care and referred elsewhere. However, patients who were refused care were not tracked individually to ensure that they received care from more "appropriate" sources. Instead, the success of the intervention was evaluated in terms of the reduced numbers of patients who returned to the ED and the reduction in overall numbers of "nonemergency" patients (Derlet & Nishio, 1990).

The biomedical stance assumes that health is an individual good and that individual behavioral intervention is the answer to the perceived problem of heavy users of ED services and the associated overcrowding of facilities. Re-education of--sometimes scolding--individuals about "appropriate" sources of care, referral of patients to alternative medical care sources, and refusal to provide services are the preferred forms of intervention. The rather obvious question, from a behavioral point of view, of whether patients return to the ED because their needs *are* being met or because their needs *are not* being met seems to be largely sidestepped, and the social context within which this behavior occurs is ignored.

The Public Health Premise

In what I will call the public health view, persons are acknowledged to be interdependent beings whose activities are best understood in the context of their communities. While individual responsibility is still held to be important, health is viewed as a social good, the manifestations of which--or lack thereof-- have much to do with social status and situation (Syme, 1990). The focus of this view is on the social and physical environmental factors that contribute to health problems on a community level. Questions tend to be framed in terms of how a problem affects the community rather than how it affects individuals. The public health mission is "fulfilling society's interest in assuring conditions in which people can be healthy" (Institute of Medicine, 1988, p. 7).

Consistent with our theoretical formulation, such a view will also attribute causality to public health factors. "Individually oriented programs," according to Syme, "do nothing to deal with *the environmental factors that initiated the problem*" (Syme, 1989, p. 222, my emphasis). The recent emphasis on primary health care may be seen as a reaction against the biomedical premises of health care (Heggenhougen & Shore, 1986).

In this perspective, the problem of heavy users of emergency services is likely to be interpreted not as a problem of certain individuals who "abuse" the system, but instead as a symptom of deterioration in the system itself--the public health and social services sector. Researchers whose background understanding is weighted heavily toward these premises tend to frame problems in terms of "access" or traditional public health concerns (deAlteriis & Fanning, 1991; Himmelstein & Woolhandler, 1995; Richman, Roderick, Vistor, & Lissauer, 1991; Thorpe, 1990). For example, the impact of the widespread destruction of single room occupancy hotels in major urban areas, with its documented effects on existing social networks, has been linked to the problem of heavy emergency service utilization, as have the deinstitutionalization of the chronically mentally ill and the subsequent cuts in community mental health services (Bachrach, Santiago, & Berren, 1990; Crystal & Beck, 1992; Wallace, 1990). Andren and Rosenqvist (1987b), conducting research in Sweden, a country with universal access, noted a link between several indicators of social disintegration (high unemployment, residential stability, and immigration in a neighborhood) and heavy ED use. Lower occupational class and housing tenure were also associated with heavier ED use in a comparison study carried out in Britain (Green & Dale, 1992). As Linder notes in his analysis of the injury problem, in the public health perspective "emphasis is placed on the interaction of factors rather than on the sufficiency of any one" (1987, p. 284).

Preferred interventions focus on environmental reform and restoration of preventive services, such as local clinics, social services and mental health programs, housing programs, and employment (Robert Wood Johnson Foundation, 1986). Within this perspective, emergency services are considered one aspect of a public health program. One participant in an American Hospital Association conference on hospital EDs held in 1972 argued that:

> people whose houses burn down are not asked to totally support the fire department...Why, then, are the sick and the facilities that care for the sick asked to foot the entire bill for round-the-clock availability of emergency medical services? Is it time to say firmly that this is a public service rendered to the

> community at large and should be supported by public tax dollars? (American Hospital Association, 1973, p. 7).

The Legal Premise

The legal view accords primacy to the protection of individual civil rights, including the right to medical treatment in an emergency if such treatment is offered as available. Individuals are viewed here also as rational, autonomous beings, but the emphasis here is on individual rights rather than individual responsibilities. There is no constitutional right to health care in the United States, but broad notions of equality and contractual obligation have created statutory rights.

There is also no legal requirement that a United States hospital offer ED services, but if one does, it must meet federal and state standards which generally require that care be provided regardless of the patient's ability to pay. Over 90% of "community" hospitals in the United States do offer emergency services (American Hospital Association, 1992). For the most part, hospitals in the United States are viewed as community services with a duty to treat anyone who presents for emergency care, regardless of their economic or social circumstances. In doing so, providers are expected to adhere to accepted standards of practice, including carrying out actions considered to be "reasonable and prudent." While at least one legal consultant has suggested that "the law will...be somewhat understanding if a patient sustains a complication as a result of an overcrowding or diversion problem" (George & Quattrone, 1992a, p. 350), the threat of negligence or malpractice lawsuits has led to well-documented efforts on the part of providers to practice in such a way as to "cover" themselves against such threats (George & Quattrone, 1992b; Tammelleo, 1992). So-called "Good Samaritan Laws" developed in most states to protect caregivers from lawsuits related to emergency aid situations they encounter as passersby, but such laws do not extend into the ED itself, where providers are generally held to a higher expected standard of care.

Particular problems are presented by patients who are perceived as "difficult," including alcoholics, psychiatric patients, narcotics abusers, and "street people" (Mayer, 1990). Such patients, who are overrepresented among heavy users of emergency services, represent medicolegal dilemmas, since their ability to give informed consent or to refuse treatment may be questionable for various reasons.

During the 1980s, as economic pressures on hospitals intensified with regulatory changes, the problem of "patient dumping"--the practice of transferring medically indigent patients from private hospital EDs to those of public hospitals--attracted the attention of researchers, attorneys, providers, and lawmakers (Himmelstein, et al., 1984; Relman, 1985). As a result of widespread media attention to the practice, Congress prohibited economic "dumping" as part of the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 (P. L. 99-272) and required hospitals to provide emergency care to all patients (Brown, 1990; Schneider, 1989). Amendments to this law in 1989 and 1990, and court cases which extended its parameters, have focused on the issue of medical vs. non-medical (e.g., economic) motives for patient transfers (Annas, Law, Rosenblatt, & Wing, 1990; Jain & Hoyt, 1992). In a move that calls attention to the conflicts between perspectives, physician groups have objected to the broader interpretations of these laws, arguing that they interfere with physician autonomy in medical decisionmaking (Jones, 1989).

In spite of these objections, trends indicate that legal protections for emergency patients are expanding, albeit via "judicial incrementalism" rather than explicit policymaking (Cross, 1992; Strobos, 1991). More recently, advocacy groups for the indigent have exerted legal pressure and the threat of lawsuits to prod counties into extending Medicaid eligibility and hospitals into providing increased indigent care (Mayster, Waitzkin, Hubbell, & Rucker, 1992). The effects of federal tax policy regarding nonprofit hospitals and charity care have also come under scrutiny (Fox & Schaffer, 1991).

In this view, then, the problem of heavy users is seen as related to the increasingly civil rights-oriented issue of access to care. Heavy use of services, in and of itself, is not a problem from a legal standpoint; a problem arises only when actions taken by institutions or providers may be interpreted as negligence or breach of duty. As in Linder's analysis of the problem of injury,

> the causal framework of the legal view...rests squarely on an interaction between identifiable parties. While environmental factors may play a role, they are relevant only to the extent that they serve as a mediating element in this interaction (1987, p. 286).

The problem tends to be analyzed from the perspective of affected classes of citizens and preferred interventions involve legislative and regulatory activity, legal education and advocacy, and lawsuits on behalf of individuals or groups.

The Market Premise

This fourth understanding of the situation sees health care in general as a result of various forces affecting the supply and demand of health care products and services. Medical care is transformed from a social good to an economic good (Annas, 1986). This view suggests that the etiology of problems related to the phenomenon of heavy ED use is an improperly functioning market due to "unfair" competition (Lewin & Lewin, 1990) or to misguided regulation. Health care services are seen as products or resources, and patients, companies providing insurance for employees (and, to some degree, physicians) are seen as self-interested, rational consumers who are motivated to "shop" for the best services at the most reasonable cost (Ellwood & Enthoven, 1995).

Heavy use of ED services is, in this perspective, a problem only because of specific associated characteristics, e.g., the fact that heavy ED users appear to represent a vast source of "uncompensated care" for hospitals and that the "cost shifting" formerly engaged in to recover these losses has been curtailed by procompetitive reforms in recent years (Wilensky, 1990). Also alleged to have contributed to the problem are various incentives that, in the U.S. system, tend to encourage ED use over use of other types of services, such as relatively liberal benefits for ED care as compared to other outpatient care in most public and private insurance schemes. (This is not the case in many countries with universal national health care coverage).

In recent years, there have been attempts to remove such incentives, with some state Medicaid programs instituting limitations on coverage to "true" emergencies; however, little outcome data is yet available to show whether this approach will prove effective in reducing utilization or whether it will simply shift clinical, ethical, and economic liability to hospitals, which are reluctant to act as gatekeepers in an increasingly litigious climate. The widespread implementation of managed care plans aimed at controlling Medicaid costs and improving access is primarily a market-focused effort (see Chapter Two).

As one would expect, appropriate interventions according to the market perspective are aimed at market adjustments, often proposed through mechanisms of increased privatization of medical care programs funded with government dollars (Ellwood & Enthoven, 1995).[4] Interventions are based on the premise that costs will go down if providers and hospitals can become more competitive by decreasing losses, maximizing profit margins, increasing efficiency, controlling costs, and developing and marketing new products (Chilingerian, 1992; Reilly & Legge, 1982). To decrease losses related to the provision of ED services, various cost sharing (O'Grady, Manning, Newhouse, & Brook, 1985) and "gatekeeping" plans have been proposed and tested (Badgett, 1986; Douglass & Torres, 1994; Gadomski, Perkis, Horton, Cross, & Stanton,

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[4] Estes (1991b) draws attention to the ideology of the Reagan presidency, which emphasized economic crisis and budget cutting and decisively shifted the national discourse on health care toward a market orientation.

1995; Hurley, Freund, & Taylor, 1989; Hurley, Freund, & Paul, 1993), with mixed results. For example, Gadomski et al. (1995) found that while no adverse effects occurred among a group of pediatric patients denied ED care under a gatekeeping model, subsequent ED use by this group was unaffected. They also found that rates of hospitalization were increased in the denied group, suggesting a penny-wise, pound-foolish result.

To maximize the likelihood of profit, schemes to improve reimbursement for heavy users of services by adjusting for prior use or for route of admission have been suggested (Anderson & Knickman, 1984; Stern, Weissman, & Epstein, 1991). Another proposal has been the creation of indigent "pools" to broaden the reach of insurance coverage (Lewin & Lewin, 1990) or other development of new "products" in insurance. Studies have also drawn attention to the need for incentives to encourage physicians to make more efficient use of resources (Ashby & Lisk, 1992).

Critics of this orientation charge that it ignores the devastating effects of poverty (Weissberg, 1991) and that there are moral conflicts inherent in taking a market approach toward a service the use of which cannot be compared with shopping for items (Iserson, 1992; Relman, 1990). Further, as Relman points out, "in business, success is measured in terms of increasing sales volume and revenues--the last thing we want to see in the health care system" (1992, p. 105). Stone (1993) argues persuasively that the dominant vision of distributive justice in the United States insurance system, emphasizing the logic of actuarial fairness, has in fact had the effect of creating and perpetuating cultural and social segregation.[5]

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[5] Further discussion of the literature on the problem of heavy users of emergency services will be found in Chapter Two.

Dimensions of Conflict

The foregoing discussion makes it apparent that framing the problem of heavy users of emergency services involves complex, potentially conflicting premises. However, again following Linder (1987), I will attempt to further this analysis by examining three dimensions along which the differing perspectives assume contrasting positions. For the problem of heavy users of ED services, I suggest that these dimensions may be responsibility, efficiency, and justice. This is not to suggest that there are not other dimensions to the problem. The analysis which follows points up, for example, the need for an additional dimension: an ethic of care to complement our ethic of justice. However, in my evaluation of the literature related to this problem, these dimensions seemed most prominent in contemporary discussions, and thus they provide part of the cultural background understanding that informs this work.

Responsibility involves judgments about the locus of accountability for the problem's existence and resolution. This dimension encompasses understandings of the relationships between the individual and families, institutions, communities, and the state. If this dimension is characterized as a continuum, one end would represent the extreme of absolute, radically free choice and individual responsibility for problems affecting individuals, while the other extreme would represent forms of collective responsibility for all problems affecting citizens. As I have interpreted them, the biomedical premise is weighted heavily toward the individual responsibility end, as is the market premise, while the public health premise lies toward the collective end, and the legal premise takes a position somewhere in the middle.

Efficiency focuses on the degree to which the value of organizational productivity enters into problem construction within the four views. Clearly, efficiency is the prime value within the market view and to some extent within the biomedical view; it is a particularly valued quality in the ED setting, where constantly shifting priorities dictate patient flow. Efficiency has little obvious bearing on the problem from a legal perspective. The public health perspective is more difficult to evaluate. While arguments have been made for increased general social productivity based on increased general public health, such claims are difficult to validate through research. Public health is "slow and steady, cautious by nature...rarely amenable to the quick fix approach" (California Coalition, 1989, p. 3); public health policy arguments have tended to focus instead on arguments of responsibility and justice.

Justice, the third parameter along which discussions about the problem of heavy ED use cluster, involves the extent to which explicitly moral arguments are a part of problem construction. The biomedical view, heavily laden with notions of "value-free" scientific objectivism, tends to discount moral arguments as based on subjective determinations which have no intrinsic relevance to the scientific medical endeavor, although as we have seen, moral evaluations of social worth are implicit in the clinical use of terms such as "noncompliance" and "abuse." The public health perspective, by contrast, relies rather heavily on moral arguments about social values and distributive justice (Brown, 1986; Forster, 1982) or what Stone (1993) has called the "solidarity principle." In the legal premise, implicit moral judgments are centered around the shifting interpretations of moral agency and the role of the state in ensuring equality. Finally, the market perspective, like the biomedical one, tends to deemphasize (some say *mask*) the moral in favor of the practical aspects of "good business."

This dissertation suggests that an imbalance is developing between these dimensions whereby efficiency, measured predominantly in economic terms, is rather lopsidedly the standard to which all other aspects of the problem are subjected and to which advocates of, for example, public health and biomedical perspectives are expected to speak in structuring policy arguments. Yet we lack adequate measures of costs over the longer term and the wider sociohistorical frame. The experiences of heavy users of ED services are instructive insofar as they help to uncover the ideological underpinnings of the press for efficiency, and some of its contradictions. For example, the findings of this study suggest that as clinicians are commanded to be more "productive" (that is, to care for more --and often sicker-- patients, in less time, with fewer staff), their ability to apprehend and respond to underlying "social" or other "nonmedical" problems is diminished, contributing to the likelihood of repeat visits and thus, paradoxically, to increased costs and reduced overall "efficiency."

Resolving the "problem" of heavy users of emergency services is crucial to the success of health system reform efforts. Yet the "problem's" social construction also reflects the peculiar conflicts of the larger health care reform debate in the United States. Jacobs (1993), among others, has pointed out that public support for universal access to health care is tempered by a pervasive mistrust of government, contributing to virtual impasse in reform efforts taking universal access as their goal. It is of interest to note that in a number of Northern European countries, where a more communitarian social ethic has long been basic to health policy discussions, there is a new push toward market-based competitive reforms based, at least in part, on some of the same concerns around efficiency. In these countries, however, these reforms are envisioned as "planned markets" involving competition between publicly owned providers (Saltman & Von Otter, 1992), usually within a comprehensive social services system.

It must be observed here that the "sagging safety net" of the United States ED did not just begin to sag; it has been doing so for a very long time. In a 1972 article titled "Emergency Departments and the Non-Emergency Deluge," the author emphasized that

> The emergency department...is now the point of entry to the health care system for greater numbers of people each year...the main impetus has been failures...in the system---lack of doctors and clinics, for example. People who get sick today often have only one place to turn: they become outpatients in an emergency department. And in many hospitals throughout the country, these departments are sagging under the demand (Emergency Medical Services, 1972, p. 25).

Conclusion

If, as Linder suggests, "the recipe for overcoming policy inertia involves both low levels of intramural disagreement and high levels of cogency" (1987, p. 295), those who are concerned with the problem of heavy users of ED services (as with health care reform generally) must find areas of common ground along the dimensions of a larger social definition (Berger & Luckman, 1966). Currently, crisis rhetoric is the one consistent commonality. The differences lie primarily in the region of dimension: for example, in the market understanding, the crisis is in efficiency; for the public health understanding, the crisis is centered around justice. Yet if, as we have seen, the problem has been ongoing for more than twenty years, can it still be called a crisis? Estes, among others, has drawn attention to social, economic and political stakes involved in crisis definitions by groups with different interests (Estes, 1979, 1991a, 1991b). Linder emphasizes the essential point that

> in a pluralistic political system, there is no one policy maker or set of presumptions that can guarantee success. Accordingly, a high level of cogency rests on convincing a large enough number of policy makers to precipitate action. A low level suggests that too few have been convinced. When intramural disagreement is high...there is wide variation in the nature of the proposed interventions; conversely, when disagreement is low, similar interventions are likely to be represented...When both cogency and intramural disagreement are high, many policy makers may be convinced, but on a wide range of proposals. The optimal situation is for many to be convinced on a similar set of proposals. The convergence in arguments connected with low levels of intramural disagreement facilitates the policy accommodation necessary to build stable majorities behind government action (1987, p. 295).

Such policy accommodation, I suggest, further involves differential power bases and the overall climate within which the negotiation of social problems takes place. For much of the past fifteen years, values of efficiency and personal responsibility--market and biomedical premises--have dominated government policymaking in relationship to health care and other issues. At the same time, with the rise of what Relman (1990) has called "the new medical-industrial complex", the prospect of a powerful liaison between market interests and biomedical interests has become a reality.[6]

This study aims to contribute to the discourse of health policy and clinical practice by calling attention to the person-level effects of some of these new liaisons and by raising questions about the way the problem of heavy ED users reveals larger social and moral issues, both within and outside of the medical care sphere.

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[6] Managed care, for example, is widely viewed as a threat to traditional physician-patient relationships, yet it often also offers financial incentives to physicians to minimize care/costs, an attractive prospect in an era of increasing competition among providers, but one which has created a flurry of concern about ethical issues (American Medical Association, 1995; Clancy & Brody, 1995; Emanuel & Dubler, 1995).

CHAPTER TWO

REVIEW OF THE LITERATURE: ECONOMIC IMPLICATIONS

> *Nurse: Well, the system kind of fights itself. It's your typical, the left hand doesn't know what the right hand is doing. Welfare has two programs that clash with each other. One is, if you're on welfare and you need transportation to the hospital, you need to call a taxi cab, if you don't have other transportation. You don't need an ambulance but you need transportation. You call a taxi cab. The rules are, you have to take that taxi cab--the taxi cab will only take you to the closest emergency room.*
> *Int: Oh, really?*
> *Nurse: On the other side of that same deal, the taxi cab has now transported a patient to the closest emergency room which might be [hospital] emergency room, but their care is restricted to the [other] hospital. A hasn't got together with B and said, if you've got a client whose care is restricted to [hospital A], don't take them to the closest emergency room, take them to [hospital A]. But when they set up the program, the assumption, because, you know, they're not being realistic, is this person urgently needs to go to the emergency room, uh, and they're not so bad they need an ambulance, but they're bad. Then let's get them to the closest hospital. Not realizing that this same group of people is going to take that taxi cab for a headache they've had for a couple of months, or for an infected fingernail, or, or, you know, a cold, or something that doesn't need to be in the emergency room.*
> *Int: Isn't that interesting?*
> *Nurse: Yeah, and it's kind of like having, uh, safety equipment that beeps when you're in reverse, and then putting earplugs in everybody.*

Introduction

As noted in the preceding chapter, heavy users of emergency services are likely to be poor. Their ED visits are thus less likely than those of average users of services to be reimbursed by private insurance. Because of the volume of services they use and the uncertainty of reimbursement for them, this population represents a significant economic risk to hospitals, especially those serving the poor. However, almost nothing has been published about this group's specific contribution to health care costs. This chapter extends the review of the literature from the preceding chapter, putting special emphasis on economic issues; reports findings from a small study on heavy ED users in one public hospital, and discusses the gaps in the literature.

Background: The Almshouse Role

As Rothman (1990) has observed so astutely, hospitals originated as shelters for the poor, and they retain traces of that mission today. Rothman notes that

> to this very day, the hospital, not only the public institution, but the voluntary one as well, has been unable to slough off or escape its initial obligation. It still must serve not one but two very different purposes: It must relieve the poor even as it cures the sick. Those who are without resources...are increasingly dependent on the hospital not only for its medical services but also for its social services, for relief not only of bodily pain but also of social deprivation. The hospital, in other words, remains in the business of charity even as it devotes itself to science. It retains its almshouse duties even as it invests its resources in high technology (p. 151).

Perhaps nowhere else in the hospital is this dichotomous purpose more apparent than in the emergency department, the often abrasive junction between hospital and community; heavy users of ED services are, in many ways, the embodiment of this historically-rooted conflict. But in addition to the issues of legitimacy and justice to which this population draws our attention, coping with the costs of providing their care may be central to the economic survival of hospitals.

The Crisis in ED Utilization

Utilization of hospital services is a hot topic in the cost-conscious 1990s, and the increasing utilization of hospital emergency department (ED) services has provoked a wave of crisis rhetoric and a flurry of articles discussing the problem of "inappropriate" ED utilization (American Hospital Association, 1992a; Buesching, et al., 1985; Koska, 1989). An American Hospital Association (AHA) study reported that 34.5% of the 808 hospitals surveyed experienced ED overcrowding on a weekly basis, and more than half were overcrowded at least monthly (American Hospital Association, 1992b). Problems of

ED overcrowding and gridlock which have been described in some regions, particularly in large, urban, public hospitals (Bindman, Grumbach, Keane, Rauch, & Luce, 1991; Gallagher & Lynn, 1990; Thorpe, 1990) may have some etiology in overutilization of this service, but it is questionable whether the "problem" would be of such interest to administrators, researchers and policymakers if the "inappropriate" users of ED services had excellent insurance coverage to pay the costs of their visits in full. Were that the case, EDs would no doubt further expand their scope and staffing and welcome all through their doors with aggressive marketing.

However, 31 million Americans had no health insurance coverage in 1987, and by 1990, that number had increased to over 34 million (American Hospital Association, 1991-1992; Moyer, 1989); current estimates are closer to 42 million. A General Accounting Office (GAO) report estimated that 14% of Americans had no health insurance coverage in 1990, but those 14% represented 19% of ED patient volume (GAO, 1993a). Since federal antidumping regulations, expensive malpractice premiums, public opinion and a litigious climate are significant disincentives to refusing emergency care services to any patient based on inability to pay for them, hospitals offering ED services face potentially significant financial losses via the ED (Saywell, Zollinger, Chu, MacBeth, & Sechrist, 1989; Saywell et al., 1992). One survey of hospital executive administrators reported that 53% of the executives cited the ED as the most unprofitable service they provided (American Hospital Association, 1992a). Eighty-two percent of the hospitals in the GAO survey indicated that nonpayment of ED care bills adversely affected the hospital's ability to provide ED care at least to "some" degree; 21% said the effect was "very great" (GAO, 1993a). Saywell et al. (1992) found that only 57% of total net charges for ED patients were paid within 180 days, compared with 85% for inpatient charges.

Some ED doctors, similarly, have remonstrated against federal and state anti-patient dumping regulations that they regard as intrusions into their independent medical decisionmaking (Jones, 1989). However, at least some access to medical care has for many years been viewed by the public as a right (Page & Shapiro, 1992), and in the absence of a comprehensive system of primary health care, the ED is considered the provider of last resort, the "safety net" (American Hospital Association, 1992a). Thus, despite the economic risk EDs represent, 93.5% of all community hospitals continue to offer ED services, recognizing that such services are viewed as essential by the public (American Hospital Association, 1991-1992).

Utilization Trends.

The increase in ED utilization has been remarkable, but it was perhaps most dramatic in the years when EDs were becoming established as basic features of hospitals, 1954-1970, during which time ED visits increased by 308% (American Hospital Association, 1972; Davidson, 1979). An early study by Yale-New Haven Hospital researchers found that 24.6% of a representative subsample of ED patients listed the ED as their usual source of care; 16% had visited the ED three or more times in the preceding year (Weinerman, Ratner, Robbins, & Lavenhar, 1966). Since that time, the trend has continued, albeit at somewhat less stunning rates.

Between 1970 and 1979, for example, ED visits increased by 97%, while inpatient visits increased by only 17% (Gardocki, 1983). Outpatient visits, including ED visits, showed significant increases following the implementation of the Medicare Prospective Payment System (PPS) in 1983; during the first half of the 1980s, outpatient visits increased at an annual rate of 2.2%, but during the second half of the decade, the annual increases averaged 6.1% (Donham, Letsch, Maple, Singer, & Cowan, 1991). During the one-year period from 1985 to 1986, ED visits increased by 6.2% (Levit, Lazenby, Cowan, & Letsch, 1991), and from 1980-1990, ED visits rose by 21.5% (American Hospital Association, 1992a).

Growth in ED use among patients covered by Medicare, Medicaid, or with no insurance coverage has outpaced ED use increases among the commercially insured. During the period from 1985-1990, there was a 34% growth in ED use among Medicaid patients, 29% among Medicare patients, and 15% growth in ED use among uninsured patients, as compared with an 11% increase among commercially insured patients (American Hospital Association, 1993). Pane, Farner, and Salness (1991) surveyed medically stable ED walk-in patients and found that poor patients and those on public assistance were both more likely to use the ED for routine care and more likely to delay seeking care when compared with patients with higher incomes and insurance coverage.

Factors Impacting ED Utilization

Prospective Payment System Effects

Leape (1992) reminds us that "before 1970, public policy was concerned not with overuse, but with the problems of underuse of health services" (p. 363). The advent of prospective payment and the associated shift from a cost-based reimbursement to a fixed reimbursement system using Diagnosis Related Groups (DRGs) resulted in decreased admissions and decreased lengths of stay for hospital inpatients (Estes, Swan, & Associates, 1993; Weiner, et al., 1987). However, DRGs also increased the likelihood that a patient would be discharged from the hospital in unstable condition (Rogers, et al., 1990). Community based resources were thus faced with heavier care clients (Wood and Estes, 1990) at a time when funding for these sorts of resources was declining (Kotelchuck, 1989), and the phenomenon of patient "bounce-backs" to the ED setting began to be noted by clinicians.

Ironically, the attempt to control costs by using DRGs did not decrease costs per day for inpatient care, since there was an increase in case mix complexity (Sloan, Morrissey & Valvona, 1988). Outpatient utilization also increased as hospitals shifted more procedures and services to the outpatient setting; Medicare Part B expenditures (allowed charges) for outpatient hospital services increased 172% during the period 1984-1988 (Helbing, Latta, & Keene, 1991). While some of the increases in outpatient care costs may be attributable to more same-day surgeries and continuing coverage of end-stage renal disease under Medicare (which began in 1973), it seems clear that increasing ED utilization represents a significant part of these increases. The number of patients served by the dialysis program in California, for example, has actually decreased by 44.5% since 1981 (Medi-Cal, 1990).

Primary Care Access and Heavy ED Use

Researchers noted as early as 1966 that heavy utilization of ED services was linked to the availability of primary care access, and this concern has been echoed repeatedly in the ensuing years (Buechner, 1991; Davidson, 1978; Grumbach, Keane, & Bindman, 1993; Weinerman, Ratner, Robbins, & Lavenhar, 1966). Decreased access to primary care resources during the 1980s has been well documented in the literature (Ahern & McCoy, 1992; Davis, K., 1991; Freeman, et al., 1990; Perloff, Kletke, & Fossett, 1995). At least one study noted that primary care and ED use had an inverse relationship (deAlteriis & Fanning, 1991). Cohen (1989) suggested that in states with low Medicaid reimbursement rates for physician visits, outpatient care (including ED care) was substituted for physician care because fewer physicians would treat Medicaid patients. Freeman et al. (1990) reported that during the period 1982-1986, access to care decreased for the poor, black and uninsured portions of our population, especially those in poor health. One New York survey of ten poor communities, totalling 1.5 million people, found only 22 private physicians under age 65 who accepted Medicaid, had admitting privileges, and practiced more than 20 hours weekly (Kotelchuck, 1989).

Access to care has particular relevance to the problem of heavy ED use because, according to one estimate, as many as 23.5% of uninsured admissions may be preventable or avoidable (Koska, 1989). In response, a number of attempts have been made to reroute patients to appropriate primary care resources. For example, a five-city project funded 22 inner-city health centers for the underserved and showed some decreases in ED utilization (Fleming and Andersen, 1986; Robert Wood Johnson Foundation, 1986). This project did not focus specifically on the heavy users portion of the population, but almost one-third of the program participants had been regular ED or other outpatient service users, compared with 23% of the community. However, the decreases in emergency department expenditures were offset by increases in other physician/ambulatory expenditures.

Work done in Sweden with the heavy ED users population suggests that increasing primary care resources is not the only answer. Hansagi, Allebeck and Edhag (1989) reported on a referral intervention study and noted that the intervention of referral to primary health care did not significantly decrease ED utilization in the heavy users group during the year following the intervention as compared with the prior year. In fact, the researchers noted, " frequent ED visitors turned out also to be frequent health centre users and increased their number of visits still more" (p. 296).

Managed Care and Heavy ED Use

Another trend affecting access is the use of managed care delivery systems for Medicaid beneficiaries in many states, in which a physician gatekeeper monitors and authorizes care. Enrollment in such managed care programs has more than doubled in the period 1987-1992, and two-thirds of the states now have such programs; as of June, 1992, about 12% of the total Medicaid population was enrolled in one (GAO, 1993b). However, data regarding actual cost savings have thus far been inconclusive.

Edhag, Olsson, Rosenqvist, & Rosenqvist (1986) tried a medical triage intervention for all ED patients and found that while it reduced the number of tests performed, there was no effect on outpatient visits to the hospital during the one-year follow-up period. Straus, Orr, and Charney (1983) reported similar findings from their intervention referral study in the United States. Likewise, Andren and Rosenqvist (1985) noted that heavy users in their Swedish study had numerous contacts with other health care providers outside the ED.

Anderson and Knickman (1984), studying a large (n=204,917) random sample of Medicare beneficiaries, demonstrated that heavy users tend to be heavy users over time: those with unusually high expenses in one year continued to have high expenses in the subsequent years. (However, Anderson and Knickman did not separate ED expenses from other expenses.)

Hurley, Freund and Taylor (1989) conducted a primary care case management study using a gatekeeper model and evaluating effect on ED utilization. They found that the intervention decreased the probability of ED use in the demonstration year, but the probability of an ED visit *by ED users* (those who had previously reported using the ED at least once before the demonstration project was initiated) was not decreased significantly. "The fact that use for users was not so dramatically affected as a probability of use suggests gatekeeping for individuals with a propensity to use the emergency room is less effective or perhaps less suitable," they noted (p. 845). Other studies of gatekeeper models have yielded mixed results, as discussed in Chapter One.

O'Grady, Manning, Newhouse, and Brook (1985) studied the results of an experimental cost-sharing intervention in which the sample (n=3973) of persons in six geographical locations participated in an insurance program with various levels of cost-sharing. They found, as expected, that as cost-sharing decreased, emergency department services expenditures increased. This study did not differentiate between heavy users and light or non-users of ED services, a distinction that other research suggests is significant. However, given equal insurance plans, low-income people--who are overrepresented

among heavy users of ED services--had greater ED utilization. In yet another study of heavy ED users, Schneider and Dove (1983) found that for both low and high users of ED services, almost half the visits were for problems that were currently being treated in a specialty clinic.

Social-Economic Links to Heavy ED Use

The seminal work of Andren (1988) and Andren & Rosenqvist (1985, 1987a) suggests a broader focus in examining the problem of heavy ED utilization. These Swedish researchers noted not only the economic difficulties of repeater ED patients, but an overrepresentation of patients from two low-income, newly-built and populated neighborhoods, a finding they link to the possibility that these patients may have a less well-functioning social network. They also report that ED repeaters with multiple psychosocial problems were heavier users of ED services than those with fewer such problems, a finding that has implications for those patients' personal economic prospects.

Effects of Competition

Freestanding urgent care centers, which sprang up during the 1980s in response to a procompetitive climate, may have contributed to the ED-related economic woes besetting hospitals, particularly larger public facilities. As the GAO survey (1993a) points out, "these centers are not considered Medicare-participating hospitals with EDs and are not covered under COBRA [Congressional Budget and Reconciliation Acts which created anti-patient dumping regulations]; therefore, urgent care centers are not required to provide care to patients who may not be able to pay" (p. 26). Where these centers have proven successful, they have siphoned away insured patients from hospital EDs. In response, hospitals have tried to market their ED services; 67% reported having used advertising or direct mailings to try to increase the number of patients served by their EDs (GAO, 1993a).

Stigmatization of Heavy ED Users

Hospitals responding to the GAO survey reported increasing ED caseloads of patients with alcohol and drug use problems, violence, and acquired immunodeficiency syndrome (AIDS) (GAO, 1993a). Such patients are more likely than other patients to be seen as "problem patients" (Mannon, 1976), and their care in the ED setting tends to be fragmented at best and victim-blaming at worst. As previously noted, patients for whom the ED is a regular source of care are more likely to be poor, and in our culture, being poor is itself a stigmatizing condition. Heavy ED users also are more likely to be mentally ill or drug- or alcohol-dependent. Since stigmatized populations are politically unpopular and clinically unappealing, there is real risk that interventions related to their health care utilization may be framed in tacitly punitive terms (see, for example, Derlet & Nishio, 1990).

Studying Heavy ED Use: Some Considerations

Researchers' Definitions of Heavy ED Use

How many visits per year constitutes heavy ED use? Here again, there are difficulties in comparing extant studies, since they use different parameters. Hansagi and her associates defined heavy users variously as those making four or more ED visits per year or per 15 months (1985, 1989, 1990, 1991); Andren (1988) and Andren & Rosenqvist also defined heavy users as four or more visits per year (1985, 1987a). Purdie and his team (1981) defined heavy use as one or more visits per month for a six-month period. Bloom (1985) considered heavy use to be 13 or more visits per year to any provider; Ullman and associates (1975) and Schneider & Dove (1983) defined it as only three or more visits per year to an ED.

Heavy User Visits as Percentage of All Visits

Berki et al. (1980) defined heavy use as 20 or more ambulatory care visits per year. Using data from the National Medical Care Utilization and Expenditure Survey

(NMCUES), they contrasted high-volume users of various types of services with those who had low-volume or no use of services, and found that heavy users of ambulatory services (ED services not isolated) constituted 4.5% of the reference population and 5.7% of all users of ambulatory services but made 32.3% of all ambulatory visits. Zook and Moore (1980) examined a random sample of medical records from six hospital populations and determined that the approximately 13% of patients who were high-cost users of medical care consumed as many resources as the other 87%. Further, these tended toward repeated hospitalizations rather than single "cost-intensive" stays.

In the emergency department setting, one study found that 11% of patients had four or more ED visits in a fifteen month period and accounted for 32% of the total number of visits (Hansagi, Edhag, & Allebeck, 1991). A Veterans Administration hospital study of patients followed in outpatient clinics who also visited the ED found that 23% of the patients accounted for 73% of visits (Schneider & Dove, 1983). These "heavy users" of emergency services are more likely to die prematurely; Swedish studies documented that heavy ED use was predictive of a twofold excess mortality rate over a nine-year period (Hansagi, Allebeck, Edhag, & Magnusson, 1990; Hansagi, Edhag, & Allebeck, 1991).

Inpatient Hospitalization and Heavy ED Use

As might be expected considering these findings, heavy users of ED services are also more likely to require inpatient hospitalization; Hansagi and her team found that the numbers of hospital admissions and hospital days were five times higher in the heavy users group than in non-users of ED services, and seventeen times higher for psychiatric admissions (Hansagi, Edhag, & Allebeck, 1991). As many as 83% of uninsured patients admitted to the hospital as inpatients enter through the ED (Koska, 1989). Further, low-socioeconomic status (SES) patients, as measured by income, occupation, and education, are more likely to enter the hospital via the ED. Stern, Weissman, and Epstein (1991) studied 20,089 patients admitted to five hospitals over a period of six months. After Diagnosis-Related Group (DRG), severity, and SES were adjusted for, patients admitted via the ED still stayed 27% longer and accumulated 13% higher charges than other patients.

Potential for Economic Losses

Economic losses related to these patients are believed to be particularly problematic for public and county hospitals, which are obligated to treat county residents and have limited or no regulatory ability to transfer patients elsewhere. In large urban hospitals, 23% of the ED caseload during 1990 was comprised of uninsured patients (GAO, 1993a). In California, these hospitals have also suffered cuts in state funding for medically indigent adults (MIAs) (Brown & Cousineau, 1991). Yet because county facilities are often the designated trauma or burn centers in an urban area, their utilization tends to be heavier. In San Francisco, California, for example, the county hospital's actual share of provided ER services was found to be far greater than its market share would suggest (Obledo & Myers, 1982). Ahern & McCoy (1992) also found that public and teaching hospitals admitted higher proportions of patients via the ED than other hospitals.

The problem of homelessness also plays a significant role in ED utilization. A survey conducted at a New York City municipal hospital found that 42% of the inpatients were homeless (Kotelchuck, 1989). Researchers at San Francisco General Hospital found that homeless persons were 42 times likelier to be high users of services than low users (A. Boccelari, R. Okin, A. Gelb, C. Wachsmuth, & B. Stegner, personal communication, August 18, 1995). Padgett and Struening (1991), surveying homeless adults in New York City's shelters and food lines, found that 27.2% of their sample reported having used an ED in the previous six months; it is notable that 39.4% of those visits were for traumatic injuries, far more than for any other category cited.

Methodological Conundrums

It is remarkable that no studies have focused specifically on the dollar amounts expended in the care of heavy ED users, considering the contemporary imperatives of cost control and appropriate utilization. Admittedly, extracting a coherent account of the economic implications of heavy ED utilization is, as noted above, complicated by the fact that the problem of heavy users of ED services is nested within a complex of larger, interdependent problems, including access to care, lack of primary/preventive health care services, economic disadvantages and discriminatory practices, absent or inadequate social services, lack of consensus on the nature and extent of the problem, the involvement of stigmatized groups, and the primacy of the acute care medical model in everyday understandings of health and illness. Yet a careful review of the literature revealed no studies specifically addressing cost issues for the population of heavy ED services users, a first step in addressing a phenomenon that has been widely identified as an economic problem.

National and state statistics on health care utilization and expenditures rarely break out ED data. For example, California's Medi-Cal statistics reports include ED utilization in the large category of "outpatient visits," which includes office visits, ED visits, home visits and other outpatient visits (Medi-Cal, 1990). Such a method tends to obscure the higher costs associated with ED care as compared to clinic care and renders effective comparisons impossible. Further, economic data related to ED use are inconsistently gathered and reported (Brown & Cousineau, 1991). Although some hospital organizations do publish cost data (AHA Monitrend II is an example), they are incomplete and their samples are not necessarily representative. Whether hospitals themselves collect sufficient data to evaluate ED utilization effectively may be in question. Fully 37% of the hospital respondents in the GAO survey, when asked to what extent income attributable to

ED services reduced or increased reported hospital net income, replied that they did not know (GAO, 1993a), suggesting that such data were not readily available to respondents.

Heavy User Charges at One Public Hospital ED

Design and Methods

A small study examining charges for a group of heavy ED user patients was carried out in conjunction with the larger research project detailed here. Utilizing data from the emergency department database at San Francisco General Hospital for fiscal year 1992-1993, a list of all patients (n=348) using the ED 10 or more times during the year was first identified (Wachsmuth, Gelb, and Scaletta, 1993). From this list, medical record numbers of all patients using the ED 20 or more times during the year (n=68) were selected and their charge records reviewed. Unfortunately, due to the hospital's database purging procedures, much of the data on charges for fiscal year 1992-1993 were no longer readily available at the time of the review. However, ED charge data were available on most of these patients for the period from April 1, 1993 through March 31, 1994, and thus this sample examines these 1993-1994 charges for patients with a documented history of heavy ED use in 1992-1993.

Patients whose charge records included less than four visits during the 1993-1994 period were excluded, since the literature seems to support a minimum of four visits per year as constituting heavy ED use. Of 68 medical records, three were missing, 14 had no charge data available in reviewable form, and 17 showed charges for less than four ED visits, leaving 34 charts to review. These 34 records were reviewed for total charges, types of charges, dates of charges, and average per visit and per patient charges. The totals for ED charges include charges for ED room, X-rays, dressings, laboratory work, drugs, and miscellaneous items generated in association with an ED visit. They do not include doctor's charges, prehospital or ambulance charges, clinic or other outpatient charges not generated in association with an ED visit. They also include no inpatient charges.

Next, from a randomly-selected list of 266 patients over 18 years of age who had only one ED visit during fiscal year 1992-1993, each fifth record was chosen for review, resulting in a group of 52 records. No ED visits were still on file for four records; one record was not found, and four records showed no charges or were clearly incomplete; these were excluded, resulting in a sample of 43 one-time ED user records. Again, due to difficulties accessing older data, it was decided to select the most recent ED visit on file for review. This decision was based on the assumption that if heavy user data included more recent data, selecting the most recent visit for one-time users would minimize the possibility that any differences in average charges represented price increases over time. However, only 15 of these records showed an ED visit during the 1993-1994 time period used for the heavy user sample; in the interest of consistency, the others were excluded and these 15 records were reviewed and compared with the 34 heavy user records.

Findings

The 34 heavy user patients made 454 visits and accounted for charges totalling $209,587, for an average charge per visit of $462. The one-time users made 15 visits and their charges totalled $7080, for an average charge per visit of $472. Although the heavy users in this sample had a marginally lower cost per visit, the difference between the groups was not statistically significant.

The heavy user patients had visited the ED from 20-55 times during 1992-1993, with an average of 28 visits per patient, making them extremely heavy users of ED services by any definition. During the 1993-1994 period, according to the charge records, they visited between four and 46 times apiece, averaging over 13 visits per patient. Average charges per patient for the heavy user group totalled $6164, more than thirteen times the average charges of $472 for the one-time users group.

Since the entire sample for both groups was taken from the population of a county hospital, it is not surprising that the largest numbers of both groups were classified as "medically indigent adults" (MIA) who had no insurance coverage for their ED visits. However, it is noteworthy that 9.3% of the one-time users did have health maintenance organization or private commercial insurance coverage, compared to 0% among the heavy users.

Thirteen of the 34 patients (38%) in the heavy users group were hospitalized as inpatients during the 1993-1994 year; eight patients (23.5%) were hospitalized more than once. These 13 patients were hospitalized a total of 32 times and the charges for these stays totalled $365,920. Unfortunately, due to database and time constraints, no data on inpatient hospitalizations was collected for the one-time users group; however, other studies have documented a higher than average rate of inpatient hospitalization among heavy ED users (Hansagi, Norell, & Magnusson, 1985; Ullman, Block, & Stratmann, 1975).

Among the incidental but intriguing findings in this small study was that inpatient hospitalizations for the heavy users group were frequently preceded by one or more visits to the ED in the week prior to the admission as an inpatient. This could suggest that the patients had sought care for conditions which later worsened to the point that they required/justified inpatient treatment. Patients also not uncommonly had made an ED visit within the week following their inpatient discharge, suggesting the possibility of premature discharge. These last findings were noted midway through analysis of records and were not systematically evaluated on all records, but they are suggestive of a potentially fruitful avenue for future retrospective work.

Discussion

Findings from this study may not be generalizable to other settings for a number of reasons. First, because teaching hospitals are known to generate higher charges than nonteaching facilities, charge estimates may be higher than they would be at other facilities. Second, because San Francisco General Hospital is a public, urban facility, its patient population is disproportionately likely to be poor, which makes it more likely that the facility has a higher than average number of heavy user patients. (However, it should be noted that the hospital is part of a well-established network of outpatient primary care and specialty clinics.) Third, because the sample sizes were small, it is possible that the samples selected were not representative of the study populations; another small study of high users conducted near the same time found higher average charges per visit (A. Boccelari, personal communication, August 18, 1995), suggesting the need for larger studies.

However, as noted previously, heavy users of ED services tend to be poorer and sicker than other patients, and it has also been shown that the poor as a group have higher morbidity rates (Kaplan, Haan, Syme, Minkler, & Winkleby, 1987; Marmot, Rose, Shipley, & Hamilton, 1978). Since poor patients are more likely to utilize large public hospitals, the cost per visit figures from those facilities are more likely to reflect actual costs for the care of heavy users. Saywell et al. (1989) noted that 79.4% of patients with over $5000 in uncompensated care charges were treated in urban hospitals.

These figures also have not accounted for the costs of prehospital care for heavy ED users. Purdie, Honigman, & Rosen (1981) found that 84% of patients identified by ED staff as heavy users were brought to the hospital by ambulance, although since there were no findings on heavy users *not* identified as such by ED staff, the results may reflect staff bias in relation to certain types of patients. However, since it is clear that heavy users tend, as a group, to be sicker than other patients, higher actual rates of ambulance transport are likely. Average *charge* for a public ambulance transport in the City and County of San Francisco, California in 1992 ranged from $300 for a Basic Life Support level response to $500 for an Advanced Life Support-level (paramedic) response; *cost* for a response, calculated by dividing total budget by total responses, was about $324 (M. Kleiner, Chief Paramedic, City & County of San Francisco, personal communication, April 27, 1993).

Improvements in access and financing may hold promise for decreasing the use of EDs by some individuals. But Brown (1981) draws attention to the fact that when Canada instituted universal national health coverage,

> lower-income groups continued to use hospital emergency rooms and public clinics at rates greater than their proportion in the population. Nonfinancial obstacles to access--such as geographic maldistribution, closure of some private practices to new patients, preferences of many patients for their usual facilities, and language and cultural barriers between minority patients and many private practitioners--continued to direct low-income persons in disproportionate numbers to their usual sources of care (p. 25).

Such reports should sound a cautionary note for policymakers and planners who want to address the problem of heavy ED use from a merely economic standpoint; they suggest that the problem may have significant ideological roots as well. While we know a great number of "facts" about heavy users of ED services, we do not *understand* very much about them, nor about what a visit to the ED means in the context of their lives. Unless and until we do, our best intentions may avail us little in changing ED utilization patterns.

Gaps and Weaknesses in the Literature

Almost no studies in the United States have specifically examined heavy users of emergency services as a distinct population. Most of the work in this area has been carried out in the Scandinavian countries, where there are important differences in the health care and social services systems, and in the cultural understanding of the individual, as compared with those of the United States. This fact is of some research interest in itself, given the negative stereotypes of many of the people known to be part of the heavy ED users group. Morbidity and mortality data for heavy ED users as a group have not been systematically collected in this country. Such data would be useful in drawing comparisons with extant data from Scandinavia.

Further, most large studies of service utilization in this country do not break out ED utilization data from other outpatient services utilization data. This is significant because the average costs associated with ED visits are assumed to be considerably higher than the average costs of a clinic visit (Baker & Baker, 1994).

Most hospitals have not in the past collected data on their individual "high user" patients, nor have state Medicaid programs been required to include person-level data in reports to the federal government, which, as Hurley, Freund, and Paul (1993) have pointed out, means that certain kinds of analyses, such as examining selection bias, cannot be carried out.

Studies are needed that systematically examine the patterns of ED use immediately before and after inpatient hospitalizations to shed light on possible weaknesses in the community services setting and/or weaknesses in discharge planning. We should also be collecting data that distinguishes heavy ED users from infrequent users, and helps us understand more about how they are different.

However, as noted above, the most glaring gap in research lies in the lack of studies which focus on noneconomic elements and instead explore the human dimensions of heavy ED use. Entirely absent from the literature are studies which attempt to understand the phenomenon of heavy ED use from the perspective of the person who uses ED services frequently. Also, while there have been a number of excellent qualitative studies focusing on subpopulations such as the homeless, chronic alcoholics, and the homeless mentally ill, no studies to date have made the social construction of the problem of heavy ED services use a point of inquiry. This study was undertaken to fill this gap by furthering understanding of this group of persons and fleshing out the practical dimensions of the problem(s) of heavy users of emergency services.

CHAPTER THREE

THE PHENOMENOLOGICAL SELF: AGENCY, IDENTITY, AND COMMUNITY

Contrasting Notions of Personhood

Padgett and Brodsky (1992) point out in their review of the literature on non-urgent ED use that much of the research on the overlapping populations of "problem" ED users assumes the perspective of the medical care provider, resulting in uncritical use of implicitly ideological terms such as "ED abuse" and "noncompliance." (Mannon's (1976) study is a notable exception.) That perspective will not be absent herein, but its assumptions are challenged by many of the findings of this study. Most studies of the problem of heavy ED users focus on identifying and counting up characteristics of people who come often to the ED, using "objective" survey, diagnostic and demographic data. Such research ignores the social- and situationally-rooted aspects of individual behavior (Lindheim & Syme, 1983) and assumes that "problematic" social behavior can be understood by explaining the personal characteristics or cognitively-formulated beliefs of individuals.

The reductionist Cartesian roots of this view of persons have been amply critiqued across the human science disciplines, including nursing (see Benner, 1985; Benner & Wrubel, 1989; Dunlop, 1986; Dzurec, 1989; Kidd & Morrison, 1988; Moccia, 1985). Yet much research in the human sciences remains explicitly or implicitly reductionist in design, perhaps due to the overarching dominance of the biomedical model in our cultural constructions of social problems (Gordon, 1988; Sullivan 1986). This research approach, in which "the categories of the culture under study are also the categories used to study it" has been attributed to biomedicine's facility at "making the social invisible"; that is, its ability to create an "aura of factuality" in which implicit assumptions about persons, body, disease, agency, and society are unquestioned (Rhodes, 1990, p. 164).

Human science researchers across many disciplines have labored to overcome the ideological dominance and the multiple limitations of the biomedical "received view." Such theoretical formulations as sick role behavior (Parsons, 1964), distress syndromes (Mechanic, Cleary, & Greenley, 1982), explanatory models of illness (Kleinman, Eisenberg, & Good, 1978), sense of control (Syme, 1989), coherence (Antonovsky, 1979), somatization (Kirmayer, 1984) and many others all attempt, with varying degrees of success, to attain a more holistic grasp of human behavior related to situations of illness or injury. Most of these, however, remain subtly burdened by dualistic notions of persons as subjects possessing selves, set over against an objective reality; by mind/body distinctions which contradict the lived experience of embodiment (Doolittle, 1990, 1994; Kesselring, 1990; Weiss, in progress) and by cognitivist constructs that fail to account for the tacit character of everyday understandings.

The Self

Perhaps most critical for the present study is the notion of the self. Biomedicine in general, and most interventions targeting heavy users of emergency services, are based implicitly on a view of the self which is grounded in Cartesian assumptions about personhood (Gordon, 1988). Guignon (1983) has called this view "subjective individualism." This view is central to our taken-for-granted understanding of ourselves, particularly in North American culture. Heideggerian hermeneutic phenomenology, which provides the philosophical underpinning of this study, challenges this view of persons; therefore, it is essential to distinguish between these very different understandings of what it is to be a person (Leonard, 1994). The reader is referred to the work of Hubert Dreyfus and Charles Taylor, among others, for more detailed explication of Heideggerian thought and its relevance to the modern identity.

While a comprehensive treatment of these contrasting notions of personhood would involve philosophical debates ranging far beyond the scope of this dissertation, it is crucial to address them, because the explication of a problem *as* social problem implicitly suggests moral judgments. These judgments, in turn, are grounded in a culturally-embedded understanding of personhood, community, goodness and badness, rightness and wrongness. However, drawing attention to our interpretation of personhood, identity, selfhood, and agency should not be understood to imply that we can simply switch from one view to another. As Taylor (1988, p. 7) points out, we are all deeply imbued with a modern form of self-understanding he calls "the disengaged identity." What can be hoped for is a wedge that opens up the limitations of such an identity and permits other possibilities of self-understanding to show up for us--and also, perhaps, permits us to see the Other differently.

The Cartesian View of Self.

Descartes (1641/1977), whose doubting subject sought both ontological and epistemological assurance in a kind of disembodied, decontextualized thinking, may be said to be the father of modern notions of personhood and identity. As Bordo (1987) has so elegantly reminded us, Medieval people did not view the world "objectively" from a position of "subject" as we tend to assume we do, but instead related to the world from within a position of involvement and interconnection, "in which the conventions of language and art therefore stressed the symbolic continuities between physical events and spiritual aspirations rather than the spatial and temporal relations between individual things" (p. 69). In art, for example, there was no notion of "perspective" to define the viewer as separate from the viewed. The world of the Middle Ages was a snug, orderly one, for all its conflicts; humans experienced themselves as part of a meaningful story involving God and Man.

What Bordo describes is a time in which morality is the warp and human activity the weft in a tightly-constructed fabric which not only defined the relationship between Man and God, but constituted existence: an era of supreme ontological security, if not one of physical security. This fabric was unraveling by the time Descartes wrote his *Meditations*, rent by scientific work which not only displaced humans from their home in the center of the universe, but more significantly, displaced the center itself. Bordo's thesis is that Descartes' reductionist solution to the problem of doubt was a defense against a cultural loss of connections. This is particularly interesting since much of the modern "identity crisis" has to do with just such a felt loss of connection.

The modern notion of identity, carrying forward Cartesian atomism, according to Taylor (1988), involves understanding individuals as essentially independent of society and nature. Gordon (1988) describes this further : "Like the atom, the self is considered a thing (an essence, not a process), often composed of elements, such as needs, values, beliefs. "(p.35). This means that the self is considered to be a subject, separate from and even in contrast with the environment, which is viewed as object. To a greater and greater degree, however, as modern psychology has influenced our self-understanding, we have objectified even this subject. We increasingly view ourselves as object/projects on which we should be working; we define our identity by separating from others to "find ourselves" (Bellah, et al., 1985). The individualism of our culture prods us to assume that people should be able to "pull themselves up by their own bootstraps" and to interpret their failure to do so as moral weakness.

Thus, as Taylor (1989) points out, we have come to regard ourselves as "having" selves the way we have hands or arms, and, I would add, we take for granted an ability to "control ourselves" just as we take for granted the ability to lift our arms or move our legs. As a growing body of research and writing on the experience of illness reminds us, however, (Benner, Janson-Bjerklie, Ferketich, & Becker, 1994; Brody, 1987; Gordon, 1994; Kleinman, 1988), these notions of absolute possession and control are simply unsustainable in the face of our everyday experience of the human condition. Our control is limited by our finiteness, our embodiment, and our fundamental inability to construct ourselves or our surrounding world "from the ground up."

Heidegger's Challenge to Cartesianism.

In contrast to this view of self and personhood, which arose out of Descartes' epistemological questions, Heidegger emphasizes the primacy of "being-in-the-world," an analytic of existence in which ontological concerns are fundamental. For Heidegger, questions of how we *know* are secondary to questions of how we *are*. "Being-in-the-world" points to an understanding of persons as situated within a meaningful world of direct experience (Dreyfus,1991; Benner & Wrubel, 1989), as opposed to understanding persons to be autonomous and "unencumbered" selves who represent an external world to themselves by way of mind (Sandel, 1992).

By "being-in-the-world," Heidegger is not talking about a subject spatially located within an objective reality.

> The compound expression 'Being-in-the-world' indicates in the very way we have coined it, that it stands for a unitary phenomenon. This primary datum must be seen as a whole. (1962, p. 78)

Instead, he is calling our attention to the fact that the very ways we understand who we are and what we are doing, the ways in which we make sense of things at all, are based on taken-for-granted understandings derived from the relationships, language, and practices of our culture (Dreyfus, 1991). This is what Heidegger means by "world." World is not everything "out there" or "not-I." We are not atomistic subjects, on this view; we understand ourselves and others because we have been born into a world in which things have significance. Without that significance, without world, we cannot truly be "selves" in the Heideggerian sense. Descartes' foundational *cogito* is an artifice; Heidegger replaces it with what he calls "*Dasein*," which may be interpreted as referring to both individual human beings and the human way of being-in-the-world (Dreyfus, 1991). This emphasizes Heidegger's rejection of the atomistic self:

> Self and world belong together in the single entity, the *Dasein.* Self and world are not two beings, like subject and object, or like I and thou, but self and world are the basic determination of the *Dasein* itself in the unity of the structure of being-in-the-world. Only because the "subject" is determined by being-in-the-world can it become, as this self, a thou for another. (Heidegger, 1988, p. 296).

The self, then, is always situated within a shared world in which things are meaningful; not, as subjective individualism would have it, set over against an objective reality which is external to it. World, as taken-for-granted understandings, is *a priori* and largely invisible to us in everyday life. We do not *attach* meanings to things, as the Cartesian self would suggest we do; meaning is *in* things already or we would be unable to recognize them *as* what they are to us. We do not think about world reflectively, except at times of breakdown or radical changes.

> World is not something subsequent that we calculate as a result from the sum of all beings. The world comes not afterward but beforehand...The world as already unveiled in advance is such that we do not specifically occupy ourselves with it, or apprehend it, but instead it is so self-evident, so much a matter of course, that we are completely oblivious of it (Heidegger, 1988, p.165).

The Constitutive View of Self

Does this mean that the self is predetermined by culture? Yes and no. Yes, in that without culture there can be no conceivable meaningful existence; no, in that things have both cultural and particular significance for an individual (Wrubel, 1985). World, as the "meaningful set of relationships, practices, and language that we have by virtue of being born into a culture" (Leonard, 1994, p. 46), is also constituted by our concerns. The constitutive relationship goes both ways. We cannot choose either our selves or world from the ground up, but we can make choices within our world, and those choices in turn may change our world. It is important to note, though, that these choices can never be entirely independent of our preunderstandings of ourselves and our world, and the limitations therein. World circumscribes those choices, mediates self-understanding, and reveals possibilities for choice (Leonard, 1994). Benner and Wrubel have called this "situated freedom" (1989).

This contrasts mightily with the Sartrean self of radical freedom, which according to Taylor (1988, p. 35)

> would be utterly without identity. He would be a kind of extensionless point, a pure leap into the void. But such a thing is an impossibility, or rather could only be the description of the most terrible mental alienation...This promised total self-possession would in fact be the most total self-loss.

Being a self is thus inseparable from being *placed in meaningful relation to* everything else, including others. This is central to understanding Heidegger's constitutive view of self and its profound contrast with the atomistic self.

> By 'Others' we do not mean everyone else but me--those over against whom the 'I' stands out. They are rather those from whom, for the most part, one does *not* distinguish oneself--those among whom one is too. ...The world of *Dasein* is a *with-world* (Heidegger, 1962, pp. 154-155, emphasis in original).

This calls our attention to what Taylor (1991b, 1994) has called the essentially "dialogical" character of self, and points to the key role of language. Language, however, is not just expressing some "inner reality" (Palmer, 1988, p. 139). Nor is it merely designative of things "out there." Instead, language discloses the world. Language is constitutive: it figures in activity, and that activity is the creation of what Taylor (1988, p. 259) calls a "public space" in which others are also. Language connects us.

We are constituted, in a very real way, by our connections with others. Heidegger uses the term 'concern' to describe this human way of being in the world. Concern means that things and others matter to us; we have meaningful involvements. These involvements, this concern, in turn point to questions about what is valued, what is good. The very question of who we are is incoherent in the absence of some understanding of goodness or worthiness, as Taylor has pointed out:

> What [answers this] question for us is an understanding of what is of crucial importance to us. To know who I am is a species of knowing where I stand. My identity is defined by the commitments and identifications which provide the frame or horizon within which I can try to determine from case to case what is good, or what I endorse or oppose. In other words, it is a horizon within which I am capable of taking a stand. (1989, p. 27)

Thus to be a self, to have an identity, to exert agency, is to reveal an orientation in moral space. Yet this morality is not a morality of deliberative or utilitarian rationalism. Instead, it is embedded in the way we live and the projects that engage us. As finite beings, we are concerned with the *point* of our lives, and, on the constitutive view of self, we live our lives as answers to that question. Human agency, as the ability of an individual to make choices based on self-understanding, is implicit in the way we take a stand on what matters to us, as Guignon emphasizes:

> Taking a stand should not be thought of as rooted in some inner plotting and calculating one's life. Heidegger would say that our self-interpretations are for the most part unreflective and unthinking. They take shape not so much in introspection as in *action* (1983, p. 91).

In the constitutive view of self, we are not born with a self; we develop and maintain a self as we develop and maintain a relationship with our world through engagement in language and practical activity. Context is indispensable to selfhood, which also means that the self is not something unchanging and permanent. This may be more understandable if we consider how different we feel in a foreign country, especially if we do not speak the language. Our practical ability to *be* ourselves through meaningful expression and activity is constrained by the limitations of our ability to communicate and be understood--recognized--by others. We lack the usual shared horizon of taken-for-granted significance, and though we may gradually learn "how it works," in the meantime we may experience an inchoate displacement.

> The world mediates my self-understanding and makes me the agent that I am. I can come to discover myself as an agent with beliefs and intentions only derivatively

> from the more primordial situations in which there is no clear distinction between agency and context of action (Guignon, 1983, p. 99).

Recognition Practices

Recognition and the Modern Identity

Taylor (1994a) has called attention to the importance of *recognition* to the modern identity. His claim is that the Western ideal of the authentic, self-generated identity, in light of our essentially dialogical development as selves, means that recognition from others takes on new importance. By "dialogical," Taylor refers to the way

> we define our identity always in dialogue with, sometimes in struggle against, the things our significant others want to see in us. Even after we outgrow some of these others--our parents, for instance--and they disappear from our lives, our conversation with them continues within us as long as we live (1994, pp. 32-33).

In an earlier age, as alluded to above in the discussion of Bordo's work, people found their identity in well-worked-out social categories that were taken for granted in the culture. Recognition was not an issue because it was part and parcel of the given social role. Now, when we understand ourselves as needing to "get in touch with ourselves," needing to heed our personal "inner voice," this recognition may be ambiguous or lacking.

> Inwardly derived, personal, original identity doesn't enjoy this recognition *a priori*. It has to win it through exchange, and the attempt can fail. What has come about with the modern age is not the need for recognition but the conditions in which the attempt to be recognized can fail. That is why the need is now acknowledged for the first time (Taylor, 1994, pp. 34-35).

Taylor is concerned in this essay primarily with the larger political realm of recognition as this pertains to, for example, culturally marginalized groups and their ability to preserve their group identities within the larger dominant culture. This level of recognition, for example, is what we are talking about when various ethnic groups demand that their cultural distinctions be acknowledged in schools and other settings. But I would like here to shift to a discussion of recognition at a more basic level.

Recognition Practices on the Individual Level

Benner (1994b) calls attention to the importance of recognition practices on the level of the individual. Such practices, according to Benner, enable the other person to show up in certain ways, both to others and to him- or herself. Recognition is central to caring about another; we cannot care if we do not recognize both the other's particularity and his or her commonality with ourselves. As self-interpreting beings, whose identities are constrained and created in interaction with others and our world, we can in the most basic sense only have an identity if we are recognized. Lacking this fundamental recognition, a recognition of oneness with another, our identity suffers, may even break down. Experientially, phenomenologically, we all know this on the most mundane level. Consider how we feel when we are the novice or the "outsider" in a group and are ignored by others. Or, on a more profound level, how in situations of bereavement, people speak despairingly of having lost part of themselves. The importance of recognition practices is revealed in the narratives of both patient and health care provider participants in this study.

Likewise, our ability to exercise agency in the world, to act, is predicated at least partially upon a recognition or acknowledgment from others that this acting is part of the possibilities open to us at this particular time. We cannot step outside of ourselves, even as we struggle to reconstruct ourselves. But the discourse we carry on with others (both in language and in activity) can create small shifts in our self-understanding, allowing us to consider possibilities that were hitherto inaccessible, and sometimes allowing parts of our own background understandings to show up in new ways. Through our engagements with others and our world, transformation is possible: rarely radical and never overnight, but possible in humbler, much more subtle ways.

The patients in this study, as will be discussed, are collectively and individually rendered invisible in many ways in our society. When they are seen in the context of a medical setting as medical or social problems that should be "fixed," their human identity is dimmed; they become for us and for themselves an example of functional breakdown, an object-body characterized primarily by deficits. What is lost is their commonality with ourselves; the meaningful context within which their behaviors make sense; their values, fears and concerns, and their contributions to our shared world. Agency, in the constitutive sense discussed here, is reduced to "compliance" with the medicalizing objectification of their bodies (Conrad and Schneider, 1992; Illich, 1976).

What is also obscured is the way our ability to recognize and care for others, and our ability to be recognized as caring, is constrained by the deficit-focused discourse that has come to dominate our understandings about medical care, a concern that is revealed in the talk of participants in this study. This deficit-focused discourse extends from the level of the individual to the system level; we speak of patients in terms of what is wrong or failing or lacking, physiologically, socially, and morally, and we speak of the system in terms of scarce resources and entitlement. On many issues, there is no clear agreement about worthy ends (MacIntire, 1984). Thus it is increasingly difficult for any of us--caregivers or patients--to envision a different kind of understanding based on moral goods.

This in turn points to larger questions about how--even whether--communities of care can be preserved at all; what we as a society want our institutions of care to provide, and for whom; and what, finally, a sustaining and sustainable community requires. This study found many stories of vulnerability, deterioration, and breakdown involving both individual persons and the fabric of society; the participants are intensely engaged in the cultural conversation about how something has gone very wrong.

A Constitutive View of Community

Defining Community

The foregoing discussion begs the question of what a constitutive view of community would involve, and how this could be reconciled with the individualistic values that dominate our cultural self-understanding. Sandel (1992) has suggested that such an understanding of community would

> describe not just a *feeling* but a mode of self-understanding partially constitutive of the agent's identity. On this strong view, to say that the members of a society are bound by a sense of community is not simply to say that a great many of them profess communitarian sentiments and pursue communitarian aims, but rather that they conceive their identity--the subject and not just the object of their feelings and aspirations--as defined to some extent by the community of which they are a part. For them, community describes not just what they *have* as fellow citizens but also what they *are*, not a relationship they chose (as in voluntary associations) but an attachment they discover, not merely an attribute but a constituent of their identity (p. 150).

However, as SmithBattle has pointed out, "the role of community in sustaining our lives often falls outside the logic of normalizing science" (1992, p. 351). Community cannot be measured or quantified; it is temporally unstable; it consists of meaningful commonalities, but we struggle to name them. Participants in this study revealed a deep longing for a kind of community they have difficulty describing except in terms of what it is not; namely, the increasingly violent, brutal and alienating world from which people are brought to the emergency department and into which they are discharged. The findings of this study further suggest that the hospital itself may be viewed as an outpost of constitutive community; one social services worker exclaimed,

> *But this is also like a--it's like a village here. It's like a village--it's that for me, too. (laughs) I can't differentiate! I work here for the same reasons a lot of people probably hang out in the emergency department. Um, there's so much vitality here.*

Community, in this sense, implies a deep appreciation for our commonality, a link with tradition and a sense of place. Sandel emphasizes that

> a community cannot always be translated without loss into an 'association,' nor an 'attachment' to a 'relationship,' nor 'sharing' to 'reciprocating,' nor 'participation' to 'co-operation,' nor what is 'common' to what is 'collective.' ...Where 'collective' assets imply endowments once separately held, now ceded to society as a whole, 'common' assets do not necessarily; they need not logically presuppose a prior

> individuation. And while 'reciprocity' implies a principle of exchange and hence a plurality of agents, the notion of 'sharing' may suggest a solidarity such that no exchange need be involved, as in sharing a joke, or an aspiration, or an understanding. And while 'association' and 'co-operation' typically presuppose the antecedent plurality of those who join together to associate or to co-operate, 'community' and 'participation' may describe a form of life in which the members find themselves commonly situated 'to begin with,' their commonality consisting less in relationships they have entered than in attachments they have found (1992, p. 151).

This calls our attention back to the way our identity as persons is shaped by world. If the self, as Guignon has suggested, is "a crossing point of cultural systems in the intelligible world "(1983, p. 109), then truly "one is a self only among other selves. A self can never be described without reference to those who surround it "(Taylor, 1989, p. 35). Our identity always involves reference to a "defining community" (Taylor, 1989, p.36); thus impediments to community are impediments to selfhood.

Some of the participants in this study live lives of extremely marginal personhood. Viewed as autonomous, rational subjects, their actions or lack of actions on their own behalf are often interpreted by others as irresponsible, incomprehensible, or cynically manipulative. Understood within the contexts of their actual everyday lives, however, as situated beings whose ability to make choices is constrained by their world and self-interpretation, their behavior may be interpreted quite differently. Likewise, our dominant cultural definitions of notions like health, illness, and emergency are called into question if we accept--or are forced by circumstances to learn--the limits of our own autonomy and control.

Narratives as Sources of Understanding and Transformation

Kirmayer (1988) has argued that

> for those who accept the value of relatedness, receptivity and responsiveness rather than power, domination and control, the exploration of alternative epistemologies and conceptions of the person is a pressing concern (p.83).

Narrative accounts offer a unique access to persons' self-understandings in situations, their concerns, and the practical knowledge at work in their everyday practices (Benner, 1984, 1994a). In telling a story, the person is engaged. Heidegger (1962) suggests that there are three modes of engagement in which people interact with their surroundings: ready-to-hand, unready-to-hand, and present-at-hand. In the ready-to-hand mode, we are engaged in an activity in what Packer (1985) describes as an "essentially holistic" way:

> We are aware of the situation we find ourselves in, not as an arrangement of discrete physical objects and not as a portion of the physical universe, but globally, as a whole network of interrelated projects, possible tasks, thwarted possibilities, and so forth...we have no need for focal awareness of ourselves and our tools: both become fused into the activity (p. 1083).

In the unready-to-hand mode, something interrupts our smooth activity. Suddenly we see everything differently, because our activity is no longer progressing as it should. We must figure out what to do, depending on the context of our specific situation (Dreyfus, 1991). Such figuring, however, takes place upon the background of our particular concerns in the activity, not as some sort of context-free, principle-based determination.

The third mode is a close as we can come to the detached, theoretical posture of Descartes. In this mode, we remove ourselves from activity and reflect in a detached, theoretical, abstract way. This is de-situated understanding, the Cartesian ideal (and the foundation for traditional rational-empirical science), but it is a mode of engagement which holds little promise for understanding human activity, since activity is always deeply contextual.

Storytelling involves the narrator in engaged, practical activity with others. As opposed to the kind of abstract, decontextualized responses generated by the present-at-hand stance (as in survey research or formal, structured interviews), storytelling allows the narrator to organize the story around his or her concerns, allows him or her to take us along into the context of the story. The choices of what to tell, how to tell it, what to put in and what to leave out are not generally made in a detached, reflective way, but are based on immediate, taken-for-granted understandings of what constitutes both a story and this particular story. As Benner (1994a) points out,

> Narrative accounts of actual situations differ from questions about opinions, ideology, or even what one does in general because the speaker is engaged in remembering what occurred in the situation. Spoken accounts allow the speaker to give more details and include concerns and considerations that shape the person's experience and perception of the event. A story of an event is remembered in terms of the participant's concerns and understanding of the situation (p. 110).

The analysis of narrative data can be carried out in many ways; further discussion of the methods used in this study may be found in the following chapter. For now, I want to simply assert that allowing others to tell their stories, and attending to them, offers possibilities for transforming our understandings of one another. Story takes us into a world--admittedly a world we share, at least partially; otherwise understanding would be impossible--but a world as the Other experiences it. Story permits us to be part of that world, because it creates that "public space" of Taylor's in which culture reveals itself. Story preserves the possibility of transformation, to the extent that the "fixed" text of the story (Ricouer, 1971) reveals new meanings for those who interpret it. Thus the stories included here are not private, idiosyncratic tales of individuals; instead, our stories, like our lives, can be thought of as commentaries on the public text of the shared social world (Guignon, 1983).

To The Reader of This Study

This study begins, then, by asking the reader to suspend Cartesian disbelief, to challenge closely-held assumptions, to attend to the concerns voiced by participants and to struggle to be open to forms of knowledge other than those mapped out by traditional conceptions of science. The reader is asked to acknowledge, first, a common humanity with those whose stories are shared herein. Evelyn Fox Keller suggests a stance she calls "dynamic objectivity," which

> aims at a form of knowledge that grants to the world around us its independent integrity but does so in a way that remains cognizant of, *indeed relies on,* our connectivity with that world (1985, p. 117, my emphasis).

On this view, recognition of individual differentness is considered a starting point for understanding relatedness. The reader is respectfully requested to permit both to emerge and to consider the possibility that, as Freeman (1993) suggests, the stories that are told here derive from a moral commitment of the narrator, a judgment about the meaning of the past (and, I would suggest, the meaning of the present and future as well). However, there are not, as one might at first assume, an infinite number of different ways in which events might be emplotted; the way one constructs a narrative is not individual and arbitrary.

> Quite the contrary; there are a limited number of ways, which is exactly why we see someone caught on the horns of a dilemma rather than babbling dumbfounded at the multifarious meaninglessness of everything that has happened. What is it, we might ask, that does the limiting? In the most obvious sense, it is the narrator; he or she is the one who decides, out of the possibilities that exist, what sort of a story will be told. In a less obvious sense, however, it is the social world that does so, a world that is, as a matter of course, meaningful and morally charged in quite specific ways...We need to recognize that the narrator, rather than being the sovereign origin of what gets said, is instead a kind of passage through which those discourses presently in circulation speak (p. 198).

Researcher as Narrator

In the same way, the interpretive researcher, as one who tells the story of the stories that were told, tries to allow participants to show up on their own terms, rather than assuming a stance of omnipotence from which "truths" emanate. This is not a simple matter of printing the participants' stories word for word, because, as discussed above, context is critical to understanding. Thus the researcher in this tradition attempts to be as explicit as possible not only about the substance of the exchange that occurs in the research process, but about the background, context, feelings, and choices involved. This is what Heidegger calls the "forestructure" of understanding (Heidegger, 1962; also see Chapter Four).

The choices, particularly, take on awesome dimensions when one comes to realize that what is left out of any account of a phenomenon is as morally significant as what is included. This circumstance is by no means unique to so-called "qualitative" research, but holds equally true for any scientific inquiry inasmuch as such inquiry is carried out by and has relevance for human beings. But in, for example, statistical research, such choices remain in the background, and the illusions of "objectivity" and control are more easily sustained.

The interpretive research process, by contrast, involves a discomforting "nakedness" as one picks one's way through mountains of meaningful data. At some point, one just begins to tell the story, unsure that this is the best place to begin, unsure whether this is in fact the beginning--perhaps it is in fact the end of the story; should it be told later?--unsure what tense and voice and perspective to utilize. The realization that it is not in fact one's own story to tell, but that the researcher is, as mentioned above, a "passage" through which the stories of others may be heard, is both comforting and sobering. One enters the "hermeneutic circle" (Packer & Addison, 1989) wherever one finds a point of entry into understanding.

Likewise, the researcher can never indulge in the notion that she has finally "got it right" or "got it all." The account presented herein is bounded by my limitations as a thinker and writer, my position in time, my social class, my family background, and my profession, among other things. Accepting these limitations, particularly when I came to appreciate the depth of my obligation to participants to allow their voices to be heard, was painful for me and caused many delays and avoidances as I worried that my approach was not "good enough." Getting out of the way and letting the participants speak was more difficult than I had imagined it would be, given my anxiety to prove myself capable as a researcher; I still mourn my failings, even as I recognize some success. This account thus contains contradictions, paradoxes, and shifts in tense that seemed necessary to tell the story honestly.

My Meeting with Jack

The process of carrying out this research was thus at all levels an experience of learning, as will be discussed further in the following chapter, but a cataclysmic shift in my level of understanding occurred late in the course of data collection, when I interviewed a man I call Jack. Jack, a man who was formerly homeless, a drug addict and an alcoholic, now volunteers at one of the hospitals. I interviewed several such volunteers, all *former* heavy users of ED services, and their stories opened up a new perspective on such patients for me. Jack's story, however, was so compelling, and his moral voice so powerful, that it irrevocably re-shaped the form of this dissertation and the structure of my thinking about the issues.

Jack now lives in a skid row hotel on about $600 a month; he has no car, few warm clothes, and no family nearby. I say these things by way of context and background, not to inspire the urge to pity. Pity is tempting because it permits us to feel generosity while maintaining a barrier against the distress of genuine understanding, but it preserves a stance of distance from the pitied.

Jack leapt across that distance. Like many of the patients and former patients with whom I spoke, he was amazingly open and direct in talking about his life, but he took this openness one step further than anyone else I interviewed. Jack took *me* into his world.

He did this through a verbal *tour de force* that led me straight out of the small room where my tape recorder silently registered each syllable, and out into the world of the streets, where he helped me to find my way in a suddenly uncertain and threatening terrain. I sat transfixed for almost four hours, hardly breathing a word, as I experienced, through Jack's imaginative construction of my experience in his world, the pain and fear and helplessness of a very different kind of life. Through Jack, I met the Other, and found him disconcertingly like me, no longer someone I could view from afar.

That evening, when I went home, I felt ashamed to have so much--a house in which to live, a spouse, a dog, a garden with flowers in it. I felt much more: rage, vulnerability, confusion over the penetration of defenses I did not know I had. It was a kind of culture shock within my own culture. I still have not shaken those feelings entirely. I hope I never do.

As a direct result of my meeting with Jack, I realized that I could not organize my findings as I had originally planned, with a chapter on the perspectives of providers and a chapter or two on the perspectives of patients. Whereas in the beginning it had been useful for me to recognize the differences in those perspectives, I now realized that both groups were talking about the same concerns: they needed to talk with each other; their commonality was more significant to this project than their difference. I needed to preserve the possibility of meeting. Hence the present thematic structure evolved, which perhaps works better in some places than in others but which, I believe, helps let the people in the margins speak to those whose livelihoods depend upon there being people in the margins.

I also realized that Jack's story informed so many aspects of this work that it merited a chapter of its own. In addition, Jack speaks throughout the work, as a sort of Greek chorus. It is my hope in offering his largely unedited narrative (Chapter Five) that the reader may take the kind of journey I took, a journey from which one cannot return home alone.

CHAPTER FOUR

METHODOLOGY

Understanding...is an unending activity by which, in constant change and variation, we come to terms with and reconcile ourselves to reality, that is, try to be at home in the world.

Hannah Arendt (1994a, pp. 307-308)

It is not necessary to know everything in order to understand something.

Clifford Geertz (1973, p. 20)

Question and Method : Intertwined Decisions

Background

Practical Knowledge.

In and around the hospital emergency department (ED), patients, nurses, doctors, technicians, volunteers, orderlies, family members, friends, social workers, clergy, paramedics, clerks, medical assistants, students, administrators, and others all participate in a complex pattern of ceaseless social activity, the parameters of which are fluid, imprecisely articulated, and crudely delimited. I began from the theoretical stance that these parameters, like those in all social situations, are created, changed and maintained in *shared, tacit understandings* about who everyone is, what ordinarily takes place there and what does not, what certain behaviors mean in that temporal setting, and what particular people or groups of people are "up to." Understanding the phenomenon of heavy users of ED services, then, requires exploring the context within which this particular kind of social action takes place (Hinds, Chaves, & Cypess, 1992).

It is these everyday understandings that constitute what Benner (1984), among others, has referred to as "practical knowledge," as opposed to formal theoretical knowledge. Benner, drawing on Polanyi (1958), emphasizes that "we cannot always theoretically account for our know-how for many common activities such as riding a bicycle or swimming...some practical knowledge may elude scientific formulations of 'knowing that'" (p. 2). Benner asserts that articulating and extending such practical knowledge is critical to knowledge development in an applied discipline such as nursing. I want to emphasize that the differences between research aimed at "knowing that" and research aimed at "knowing how" are crucial to understanding not only clinical practices, as Benner's research has shown (Benner, Tanner, & Chesla, 1992), but also social practices which dovetail with the clinical world--such as the social practices involved in practical and ethical negotiation of the complex world of the emergency department by those who use it most heavily.

In nursing, as in other professionally marginalized human science disciplines, a yearning for language and research activity less trivializing to the particular and the profound, less muting to the moral, has led to increased affinity for "qualitative" or interpretive research methodologies. (I prefer the more intellectually forthright term "interpretive" rather than "qualitative" and will generally use it throughout this discussion). Such methods include phenomenology, ethnography, grounded theory, certain types of historical research, much feminist research, and others.

Though in theory there are distinctions between these methods, some of which will be discussed below, in practice and product there tend to be rather more commonalities than differences (Cobb & Hagemaster, 1987). All assume, for example, that the researcher is the primary instrument and that context is important in the study of human activity. Each attempts in some way to address the failures of "traditional" science and to escape what Lather (1984) called "hyper-rationality" (p. 59), an emphasis on formal logic to the exclusion of emotional and moral dimensions in studying human conduct. Denzin (1989) states that "postpositivist, interpretive inquiry assumes the social nature of the research process, takes account of interpretive meaning, locates language centrally in the research act, incorporates values into research, and focuses on the gendered nature of social life" (p. 69). Selection of one method over others depends on the researcher's theoretical stance, the research problem or question, and the goals of inquiry.

Culture as Background.

The notion of "culture," so basic to anthropological studies, may be compared with Heidegger's notions of "background" understandings which make things show up for us, allow things to be intelligible, and are revealed in our everyday practices and activities. In explicating the concept of culture, Geertz (1973) draws on an essay by Gilbert Ryle[7], who coined the term "thick description," in which Ryle discusses the multiple possible social meanings of winking: flirtation, furtive joking, or parody, for example. Geertz explains why such an understanding is not, as our Cartesian assumptions would suggest, a privately-held idea of an individual subject:

> Culture is public because meaning is. You can't wink (or burlesque one) without knowing what counts as winking, or how, physically, to contract your eyelids...but to draw from such truths the conclusion that knowing how to wink is winking...is to betray as deep a confusion as, taking thin descriptions for thick, to identify winking with eyelid contractions (p. 12).

I will return later to "thick description." For now, I want to emphasize that knowing what counts as winking, and in what circumstances, is part of what Heidegger calls the "fore-structure" of interpretation (Dreyfus, 1980, 1991a).

Fore-structure.

Any attempt to understand begins, Heidegger asserts, with *something* we already know; that is, we cannot ask about something if we know nothing at all about it. This, in Heideggerian terms, is our *Vorhabe* --fore-having : our taken-for-granted understanding of anything. "In every case...interpretation is grounded in *something we have in advance*," Heidegger claims (1927/1962, p. 191, italics in original).

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[7] Ryle (1949) also offers an enlightening discussion of practical knowledge in Chapter II, "Knowing How and Knowing That."

Further, we already have some perspective on what it is we are asking about. Heidegger calls this our fore-sight. Dreyfus (1991a) calls this our "point of view" (p. 199). Finally, we always already have some idea of what will count as an answer to our question; this is our fore-conception. This does not mean that we are clairvoyant, nor does it imply that we cannot be surprised or "turned around" by what we find, but it is Heidegger's argument that we must have--*in asking*--some notion of what constitutes an answer, or we would be simply unable to recognize an answer when we found it.

Thus interpretation, according to Heidegger (1962), always presupposes shared understanding. The kinds of questions that make sense to us, that seem important, that we think to ask, are themselves not determined "objectively;" they arise from the kind of person we are, the way we understand ourselves and others, our point of view, and our pre-understanding of what will constitute an answer to our question or concern (Dreyfus, 1991). This may strike the average reader as the most mundane and obvious of assertions, and Kuhn's (1977) exegesis of this argument in relation, for example, to theory choice is widely cited, yet most "science" continues to be conceived, conducted, and presented as though the *scientist* was absent or irrelevant. The primary assumption of this study and the philosophical tradition in which it is embedded is that while the illusion of pure objectivity may be useful for studies of bacteria or for epidemiology, it is an obstacle in studies that seek understanding of human activity in context. Heidegger's thought thus represents a radical assault on the utility of human science based in Cartesian understandings of our relationship with the world and with our bodies.

Locating the Researcher.

In interpretive research, the researcher is the primary instrument (Lipson, 1991). What Mechanic (1989) calls the "calibration" of the researcher as instrument, then (although this mechanistic (!) metaphor is unfortunate), depends at once upon the kinds of shared understandings that inform the researcher's choice of study question(s), the interpretation of the data, and, ultimately, the reader's access to the interpretation, about which neither researcher nor reader can ever be fully explicit--again, because to be fully explicit one would have to speak from the ontologically impossible position of absolute "objectivity." In keeping, therefore, with the philosophical assumptions of the study, it is necessary here for me to consider and attempt to be as clear as possible about my own fore-structure of understanding in conceiving and approaching this work. As discussed in the previous chapter, much about my own taken-for-granted fore-structure can only be encountered in dialogue or in breakdowns in smooth functioning that jar previously unquestioned understandings--as in my encounter with Jack. The following general description will, however, help to locate me as a researcher.

I am a Caucasian woman, 44 years of age, married, with two stepchildren who are now young adults and living independently. I have been a registered nurse for eighteen years and an emergency nurse for fifteen years, working full time for much of my career and at least part-time or during summers throughout the period of doctoral study, up until the last year of work. Most of my experience in emergency nursing took place in inner-city hospital settings. My husband is also an emergency nurse and works full-time.

I also have experience in medical and community mental health nursing and my master's preparation was in community health and international/cross-cultural nursing. My educational career has been nontraditional. I entered a university immediately following high school to major in English and journalism, dropped out after two years to pursue "life experiences," and worked as a motel maid, a newspaper reporter and proofreader, a cannery worker, a nurses' aide, literary editor, and assorted other low-wage, low-status jobs before returning to school and obtaining an associate degree in nursing. I then worked for ten years as a registered nurse before returning to school to earn, over the period of the last eight years, my baccalaureate, master's, and doctoral degrees in nursing.

I will be the first person in my immediate family of origin to earn a graduate degree and the first in any branch of my family to have earned a Ph.D.

Articulating the Research Problem.

Like the narratives of the participants detailed herein, this study itself has a temporal structure. My years as an emergency nurse set up the question and allowed the phenomenon of heavy users of ED services to show up for me as a problem. It was a problem, for me, partially because I could not clearly define what the problem was, in terms of causal factors, and because, lacking such understanding, I could not see what should be done to remedy it. It was also a problem because of the moral issues these patients raised and my own ambivalence about their culpability in contributing to their problems and mine.

I thus began from a perspective of frustration, feeling that these patients had genuine needs but unable to determine, in the context of my practice, what those needs were and how they could best be met. However, even as I sensed that there might be more to the problem than was immediately obvious, my ability to see more deeply was constrained by my embeddedness in the acute care setting. It was only very gradually, after spending time with these patients and hearing their stories, that I began to see the problem in terms of larger societal issues such as the breakdown of community. And it was only at the very end of my data collection that I came to appreciate the meaningful contributions this group of people were making and/or could make to a community.

My interest in these patients also arose from a more longstanding interest in the lives of the socially marginalized (Hall, Stevens, & Meleis, 1994), which probably in turn derived from my parents' political and religious commitments and their social class. The study is also informed by my interest in the ethical aspects of emergency practice (Malone, 1993). The "regulars" whom I took initially to be the subject of my study were in fact morally and clinically puzzling to me; it was as I began to talk about those puzzles with others, in the early conceptualizing stages, that I realized that it was in fact the *problematic nature* of such patients that was the heart of my project. As outlined in Chapter One, it was clear that these patients were a problem, but it was not clear what kind of problem they were (Malone, 1995). Since problem definition is critical to any attempt to arrive at "solutions," I decided to focus my inquiry on arriving at a clearer understanding of the dimensions of the problem of ED "regulars."

Objective and Aims of the Study.

The broad objective of this study was to contribute to improved understanding of the phenomenon of heavy ED use. The primary aims of the study were to:

1) describe, in detail, the context in which heavy ED use occurs and explore the meaning of heavy ED use to patients who are heavy ED users;

2) uncover and articulate the dimensions of the "problem" of heavy ED users by examining it from several perspectives; and

3) explicate the findings within a policy perspective, including implications for health care reform.

Social Constructionism and Heideggerian Phenomenology.

The social constructionist view posits that the definitions of a problem are constitutive of that problem (Berger & Luckmann, 1966; Blumer, 1971; Kitsuse & Spector, 1973; Schneider, 1985). This notion is useful in setting up questions which focus on everyday habits, practices, and concerns because it allows the "problem" as commonly recognized to be understood as a locus of social meaning, and in terms of this narrow definition, it has played a key role in the development of this work. Social constructionism, deriving from the symbolic interactionist branch of sociology, takes "reality" to be *intersubjective*, that is, derived from the interrelationships between the meanings of individuals, and largely taken for granted. This hints at possible intersections with Heidegger's notion of *world*, but there are some significant distinctions between the assumptions of these views, which should be clarified here.

Berger and Luckmann (1966) challenge the assumed objectivity of "reality" by suggesting that external "reality" is actually the "objectivation" of "subjective processes." The struggle with language is evident. Yet, although at times they appear to come close, as when they argue that "individual consciousness is socially determined" (p. 78), they do not seem to make the more radical move of challenging the culturally sacrosanct notion of the private, individual subject. For example, they refer to persons as having achieved "subjective possession of a self and a world" (p. 137). Heidegger's (1962) notions of world and of *Dasein* (see Chapter Three) clearly reject both the private individual subject and the self of possession as artifacts of the Cartesian self-understanding.

Berger and Luckmann also assume a particular intentionality of the conscious subject. "Consciousness," they assert, "is always intentional; it always intends or is directed toward objects" (1966, p. 20). Such a notion is closer, according to Dreyfus (1991), to a Husserlian phenomenology than to Heideggerian thought:

> [Husserl] developed an account of man as essentially a consciousness with self-contained meanings, which he called intentional content. According to Husserl, this mental content gives intelligibility to everything people encounter. Heidegger countered that there was a more basic form of intentionality than that of a self-sufficient individual subject directed at the world by means of its mental content (p. 2-3).

This more basic form of intentionality is the kind of everyday "mindless" habits and actions that are taken for granted, including embodied understandings which we rarely, if ever, think about, like how far to stand from one another or how to move our arms while walking. Although Heidegger does not deny that we at times experience ourselves as conscious subjects who cognitively direct our activities, he argues that this is a derivative mode of self-understanding that presupposes the more basic experience of ourselves as embodied and situated. The intentionality of Berger and Luckmann's subject means that their understanding of meaning remains linked to the intentionalistic social exchange between the private meanings of two (or more) private subjects. In contrast, Taylor (1987) emphasizes that meaning is always in relation to a field, and uses the example of the emotion of shame to make the point that meaning is always experiential but not cognitive nor privately-held:

> An emotion like "shame" can only be explained by reference to other concepts which in turn cannot be understood without reference to shame. To understand these concepts we have to be in on a certain experience, we have to understand a certain language, not just of words, but also a certain language of mutual action and communication, by which we blame, exhort, admire, esteem each other. In the end we are in on this because we grow up in the ambit of certain common meanings (p. 43).

This distinction has important implications for researchers seeking to understand human activities, since intentionalistic mental activity or consciousness are not necessarily the route to making sense of actions. Instead, on this view, the actions are themselves implicitly meaningful and not necessarily linked with intentionalistic mental content. In turn, this points to one of the reasons surveys and questionnaires are not sufficient as tools for understanding human beings, since they rely on precisely this kind of flawed assumption about cognitive activity's relationship with embodied habits, skills, and practices.

It is also clear from the caveat offered on the last page of their now-classic book that Berger and Luckmann also still cherish the ideal of "value-free" scientific inquiry:

> In sum, our conception of the sociology of knowledge implies a specific conception of sociology in general. It does *not* imply that sociology is not a science, that its methods should be other than empirical, or that it cannot be "value-free" (1966, p. 189).

In the Heideggerian phenomenological perspective, there can, as noted elsewhere, be no "value-free" human science, inasmuch as values and meanings are not personal and subjective, but are embedded in shared practices, habits, and taken-for-granted understandings. On this view, to sever value from inquiry is to lapse into the delusion of perfect separation of object from subject--a separation which Berger and Luckmann appear inclined to reject, but never explicitly do. Garfinkel's (1967) discussion of a study of research coders showed how commonly held, implicit background understandings inform even the most carefully constructed scientific activity and are essential to the conduct of that activity.

These philosophical distinctions made, it is important to acknowledge the rich contributions the social constructionist view has made toward a critical examination of medicine's social roles. Wright and Treacher (1982) remind us that the social constructionist view of medicine challenged the assumptions that medicine is value-free and based on rational, "scientific" evidence; that what is and what is not medicine is self-evident; that diseases are natural objects, and that social knowledge is independent of medical knowledge. They discuss several different strands within social constructionism, but emphasize that "the most important single distinguishing feature of work in social constructionism is its opposition to the traditional approach" (p. 9), characterized by the above assumptions.

In this study, I have (as mentioned in Chapter One) attempted to combine the social constructionist notion that problems are defined and created by our understandings of them with the Heideggerian phenomenological notion that such understandings are primarily experiential rather than cognitive. The primary theoretical problem, then, becomes one of gaining access to understandings. Since meanings are assumed to be commonly shared by those within a culture, rather than personal and private, and since they are assumed to be embedded in culturally coherent activities rather than in cognitive processes, the researcher seeks a way to understand human activity as inherently meaningful, not merely as cognitive stimulus/response. This requires an appreciation of context and of the way people organize their narrative accounts of the world.

Interpretive Ethnography.

Ethnography is a research method originating from the anthropological tradition. Classic ethnography took the naively realist position that ethnographers could be detached observers, neutrally reporting the social "facts" of the "foreign" cultures in which they studied, a position since critiqued as ethnocentric and reinforcing of imperialist ideologies of domination (Rosaldo, 1989; Singer, 1989). Current theory in anthropology may be linked to philosophical traditions in phenomenology (Geertz, 1973, 1983, 1988), critical social theory (Baer, 1982, 1989; Morsy, 1990; Singer, 1986, 1989; Waitzkin, 1986, 1991) and sometimes to a blend of these traditions, as in the "critical-interpretive" approach advocated by Lock and Scheper-Hughes (1990) or the "macro/meaning" blend of Wright and Morgan (1990).

Geertz (1973) is best known for popularizing the concept of "thick description" as an aim of interpretive ethnography. Thick description, according to Geertz, means "tracing the curve of a social discourse; fixing it into an inspectable form" (Geertz, 1973, p. 19). The ethnographer, according to Geertz,

> 'inscribes' social discourse; *he writes it down*. In so doing, he turns it from a passing event, which exists only in its own moment of occurrence, into an account, which exists in its inscriptions and can be reconsulted" (p. 19).

This activity is what Ricoeur (1971) has called "fixing action as a text." In Ricoeur's view, the writing down of text means that the text takes on a further life of its own; the author no longer controls its interpreted meanings. "The text's career escapes the finite horizon lived by its author," Ricoeur suggests (p. 320). Such a notion can set up a range of "Cartesian anxieties" (Bernstein, 1980) for those among us prone to such afflictions, but for researchers working within the interpretive or hermeneutic paradigm, it offers instead new possibilities of human understanding, including critique. "The emancipation of the text," argues Ricoeur, "constitutes the most fundamental condition for the recognition of a critical instance at the heart of interpretation" (1990, p. 325). Dreyfus

(1991b) has emphasized, regarding Heidegger's views of science, that "different understandings of being reveal different realities or domains of intelligibility, and since no one way of revealing is exclusively true, accepting one does not commit us to rejecting the others" (p. 37).

This view has distinct advantages for human science researchers seeking to raise the often "hidden" ethical questions of social policy, or to explore the socially determined aspects of the body, health and illness (Bellah, 1982; Gilligan, 1983; Leder, 1990; Lock and Scheper-Hughes, 1990; Turner, 1989). An inquiry carried out in this tradition, if well done, may allow others to experience a situation or phenomenon in a new way. Ricoeur refers to this as "opening up a world for us," emphasizing that "to understand a text is at the same time to light up our own situation" (1971, p. 321).

Geertz (1983) suggests that this is because, contrary to popular notions, "common sense" [or what has been called "practical knowledge"] is itself a cultural system, albeit one that denies its cultural etiology. It is the task of an interpretive inquiry to uncover such dimensions of knowledge. But how is this to be done? Packer (1985) suggests that

> one task of the hermeneutic method is to push this [taken-for-granted] understanding into the unready-to-hand mode and thereby make it accessible to thematic description. One way in which this is done is by attending to what is *problematic* in the original understanding: the lacunae, the gaps, and the contradictions that, in our everyday practice, we habitually gloss over...Focusing on these has the consequence of bringing to light those aspects of the situation that we *do* understand...When we do this, we frequently find that practical activity is confusing, ambiguous, and contradictory and requires some kind of work to be understood (p. 1089).

Significant as gaps, breakdowns, and problematic areas may be to the interpretive project, however, there are other equally important aspects to be considered. Traditions, competing notions of good, and breakthroughs--where a situation changes one's perspective--can also be ways of gaining access to our own taken-for-granted assumptions (Benner, 1994a).

Geertz characterizes interpretive work as "a continuous dialectical tacking between the most local of local detail and the most global of global structure in such a way as to bring them into simultaneous view" (1983, p. 69). This method assumes that culture itself sets up how human beings interpret experience and generate behavior (Aamodt, 1991), and that the whole is always more than a sum of parts (Rabinow & Sullivan, 1987). Participant observation is the key research strategy, commonly supplemented by interviews and any other data sources (records, historical data, and so forth) available in the setting. Participant observation, as Burawoy (1991) points out, has advantages in that the researcher is able to "juxtapose what people say they are up to against what they actually do" (p. 2). We may also see what it does not occur to people to talk about.

From an interpretive perspective, however, even "what they actually do" is not always so unproblematically ascertained. Taylor (1988) has called attention to the self-interpreting status of human beings; on this view, our interpretation "is constitutive of what we are, and therefore cannot be considered as merely a view on reality, separable from reality" (p. 47, also see Chapter Three). Understanding behavior requires interpretation. This is not, however, to suggest a radical subjectivism, and at least in this Kuhn (1991) is in agreement with Taylor's view. "Concepts--whether of the natural or social world--are the possession of communities," Kuhn asserts (1991, p. 20).

The problem is that we are accustomed to a view of the self that is linked to what Taylor calls "disengagement from embodied agency and social embedding" (1991b, p. 307). Interpretive inquiry's answer to this view is that common meanings set up a world within the shared understanding of which individuals can have different perspectival concerns. Understanding, as Packer emphasizes in differentiating it from causal prediction and formal explanation,

> is not seen as a 'searchlight' that scans over a field of potential knowledge but rather as a kind of appreciation that is necessarily partial (in both senses of the word: incomplete and with its own point of view)(1985, p. 1089).

Limitations.

Here we come up against the limits of this kind of research. Interpretive ethnography does not aim nor is it suited for generating or testing predictive theory in a causal, "falsifiable" way. Theory in the broadest sense can never be divorced from the interpretive process, but the theory produced by interpretive ethnography is unlikely to be formal or generalizable. An interpretive ethnography, as research product, is a historically-situated text whose narrative value, while not limited only to the personal, private or local, is not meant to be universal. "Any final construction that would be a resting point for scientific inquiry represents an illusion that must be resisted," stress Packer and Addison (1989a, p. 35). Further, such research does not, as Van Manen (1990) cautions,

> necessarily imply that sound human science will lead to increasingly effective management or control of human behavior. In fact, just the opposite may be the case...human beings who have acquired a deepened understanding of the meaning of certain human experiences or phenomena may in fact be less susceptible to the effective management or control of others (p. 21).

Approaching the Phenomenon.

Ethnographic research approaches phenomena with a "big net" (Fetterman, 1989); the aim is to begin by learning as much as possible about the context within which the participants live, work, or interact. In keeping with this aim and with the assumptions of the phenomenological method as it is understood here, I did not attempt to set out a "conceptual framework" in advance. To do so would be to blind myself to potentially fruitful avenues of inquiry which might not fall within the preestablished framework.

Instead, I tried to approach the phenomena with an openness to having my usual ways of understanding challenged, augmented, or changed. Several broad lines of inquiry guided my approach, to wit: What are the formal and informal agreements between providers and heavy ED users? What kinds of features characterize the relationships between care providers and heavy users? How do their notions of what constitutes a legitimate emergency converge and differ? How do patterns of care for heavy users compare with care patterns for infrequent users? What can be observed about the cultural milieu if heavy ED users? How do the language and behavior of heavy users and caregivers reveal their respective understandings of their moral and social status in the situation? What larger structural factors may be at work in shaping the phenomenon?

These lines of inquiry formed part of my own preunderstandings, my own "horizon" which I have no choice but to see within and could never see at all without (Palmer, 1969). In this kind of research, the effort is made to let the phenomena lead, to follow it rather than trying to measure or delimit it. Hammersley and Atkinson (1990) describe ethnographic research as having a "funnel" structure, whereby early observations give way to a progressively more focused approach. In an ethnographic project informed by Heideggerian phenomenology, the structure is rather considered a hermeneutic or interpretive circle, with a moving back and forth between part and whole, between the initial preassumptions and what is being revealed in the data, or, as Rosaldo (1989) put it, an "interplay between making the familiar strange and the strange familiar" (p. 39). There is the mandate to go beyond existing, publicly authorized interpretations of things (Leonard, 1994). For this reason, although I was aware of at least one other study of the ED setting using ethnographic methods (Roth & Douglas, 1983), I refrained from reading that work until after my analysis was completed, to avoid unconsciously framing my findings within their pre-established theoretical grid.

Alternative Methods.

This method of inquiry was selected over several others. Questionnaire and survey methods were briefly considered and rejected because what people say about their behavior in a detached, reflective mode is very different from the kind of pre-reflective meanings they convey about themselves and their world when telling stories or engaged in conversation (Van Manen, 1990). As Vladeck (1993) observes,

> beliefs--even beliefs about very important and highly value-laden issues...--are not behavior. The two may often conflict with one another. Acknowledging that potential disjunction is hardly a breakthrough in the science of psychology, but it is noteworthy how often those who seek to reform health care fail to recognize it (p. 13).

A second problem with the questionnaire or survey approach is that context is largely left out, and thus interpretation of the meaning of a particular response is made more difficult. Mishler (1986) calls attention to the way the standard interview process "suppresses" the relevant stories people often use in order to answer a question. Understanding the context in which a response is given or a behavior carried out gives us cues as to how to interpret its meaning. Once the context of a situation is described, the number of possible interpretations is limited, with a few "best" interpretations emerging as making sense in the situation (Benner, 1984).

Quantitative study of medical records was rejected, because such a method showed little promise in terms of fleshing out larger dimensions and problematizing. Such a method unduly restricts the kinds of questions one can ask of the [necessarily limited] data. However, a small sample of medical records was reviewed; see discussion below under "Medical Records Review."

Though use of several different qualitative methods could result in useful studies of this population, interpretive ethnography has several advantages for a study with broad policy-related aims. Its emphasis on arriving at a research product that combines micro- and macro-level analyses, and its focus on description of everyday practical activity in context are two of these. Its basis in the notion of culture as a system of practical logic makes it especially compatible with the preliminary research questions that generated this inquiry. Unlike grounded theory (Strauss, 1990; Strauss & Corbin, 1990), as noted above, interpretive ethnography does not specifically seek to generate abstract theory that potentially can be formalized and generalized. Yet it has the potential to generate a rich account of phenomena that are often taken for granted and thereby rendered invisible, allowing the reader some access (though never complete access; we cannot ever step outside ourselves) to the world of those studied. Ethnography can also be used to enrich, question or confirm data obtained through methods such as questionnaires and surveys, and to provide cultural, historical, and sociopolitical context for the interpretation of statistical findings.

The Importance of Narrative.

Narrative, according to Polkinghorne (1988), is

> a meaning structure that organizes events and human actions into a whole, thereby attributing significance to individual actions and events according to their effect on the whole. Thus, narratives are to be differentiated from chronicles, which simply list events according to their place on a time line. Narrative provides a symbolized accounting of actions that includes a temporal dimension (p. 18).

When narrative is understood in this way, the stories people tell about their experiences become more than analytically useless background chatter, subordinate to the real "facts" of the case. They become an access into understanding what is (and perhaps what is not) significant for a person, since a story is told under certain aspects, about certain things, and leaving out other things. They reveal what Polkinghorne calls the "unfolding themes" of a person's experience. Benner (1994a) links people's narrative accounts of experiences with Heidegger's "ready-to-hand" mode of engagement (see Chapter Three), suggesting that stories tap into that disjuncture between cognitive belief and everyday practical activity in context.

Arendt (1958) calls attention to the intangible "web of human relationships" (p. 183) within which the "stories" of individual human beings take form. Because of this preexisting web into which we are born, Arendt argues, we are never the sole "authors" of our life stories:

> Although everybody started his life by inserting himself into the human world through action and speech, nobody is the author or producer of his own life story. In other words, the stories, the results of action and speech, reveal an agent, but this agent is not an author or producer. Somebody began it and is its subject in the twofold sense of the word, namely, its actor and sufferer, but nobody is its author (1958, p. 184).

Likewise, the "smaller," more local stories that people tell each other do not spring forth from them as idiosyncratic, private tales; they are constructed out of and fit within the "web" of relationships and they reveal not only the agent who tells the story, but aspects of the "web" itself.

Research Design

Multiple Data Sources

Multiple data sources were used in an attempt to illuminate multiple perspectives on the phenomena associated with heavy ED use. These data sources included:

1) Participant observation: observations, informal conversations with nursing and medical staff, patients, family members, clerks, and others, and the written researcher field notes generated thereby;

2) Brief audiotaped unstructured interviews with heavy ED users, eliciting their narrative accounts of their experiences;

3) A small number of more in-depth interviews and/or follow-up interviews with heavy user patients;

4) Medical records review for a subset of those patients participating in the lengthier interviews, noting demographic data, numbers of ED admissions, numbers of hospital inpatient admissions, diagnoses, patterns of use (times, days of week, month of visits), and other descriptive and quantitative data; and

5) Group interviews with nurses and other ED staff, focusing on their narratives of experiences with heavy ED user patients.

Other data points included informal discussions with social service personnel, law enforcement and security personnel, management personnel, volunteers, and prehospital care providers and observations at two alcohol detoxification facilities. Unfortunately, time constraints precluded further community-level fieldwork; I believe it might have also been productive to carry out observations and interviews at one or two clinics for the poor, some homeless shelters, and in free food lines, but this would have significantly expanded the scope of the project and its cost in time and resources.

On Triangulation

Triangulation in its most generic definition is the use of multiple methods in the same study. The term derives, according to Hammersley and Atkinson (1990), from a navigational metaphor, comparable to the way one can locate one's position on a map by taking bearings on two other points. Denzin (1989) described four types of triangulation: data triangulation, in which data is collected from multiple sources for the same study; investigator triangulation, in which multiple investigators or observers are used; theoretical triangulation, in which various theoretical perspectives on a phenomenon are considered; and methodological triangulation, in which either different scales are used within the same method, or different methods are used to examine the same phenomenon. Depending upon the type of study being undertaken, certain types of triangulation may or may not be appropriate or compatible with research assumptions (Knafl & Breitmayer, 1991). Ethnography almost always involves at least some triangulation (Fetterman, 1989).

This study used data triangulation, in that multiple data sources (observations, patient and provider interviews, medical records) were consulted in developing the interpretive account. However, it is important to emphasize that in an interpretive study such as this one, triangulation is not engaged in as an effort to get the "real" story, understood as some "objective" truth that can be verified through seeking out several accounts of the same phenomenon. Instead, triangulation in the phenomenological tradition which informs this study is a strategy for fleshing out the dimensions of a phenomenon by considering it from several perspectives, each "true" in its own way. The use of concurrent consensual validation strategies (discussed below) while doing analysis could be interpreted as another form of triangulation.

Research Settings

Selection of Research Sites

Data were collected at two study sites, each located in a different western coastal state. The sites were selected because they were both inner-city teaching hospital trauma centers serving significant numbers of poor patients. Since, as noted in Chapter One, heavy users of ED services are more likely to be poor, it was assumed that facilities serving poor patients would be likely to have more heavy ED users. It was also of interest to consider whether any obvious differences emerged in the way the problem was interpreted, or in the way heavy ED users interacted with providers, that might be related to differing state health programs or policies. In addition, I was interested in seeing if there were differences between the public hospital ED and the nonprofit hospital ED.

Our Lady Hospital

Site A, which I will call Our Lady Hospital and Medical Center, is a trauma center located in a relatively poor inner city neighborhood of a medium sized city. The hospital is also a teaching facility, offering residency programs for physicians affiliated with a nearby university medical school. Our Lady's emergency department handles approximately 35,000 visits per year and the payer mix is approximately 40% Medicaid, 20% uninsured or self-pay, 20% Medicare, and 20% privately insured. Our Lady is one of several area medical facilities owned by a nonprofit hospital corporation.

Descriptive Notes.

In the central area of the ED are two islands (stand-up level desks) with tall wheeled chairs. One island is the unit secretary and nurse work area and holds two computers, several telephones, and charts. One island is the physician area. It holds telephones, a desktop work area, and an adjacent patient/chart tracking light board system, which I am told with some pride was invented by someone who worked there. The department is all painted in soft pastels, mostly rose, beige, and lavender; the colors are somehow soothing and there is good lighting. Nursing staff all wear hospital-provided scrub uniforms and all are clean and neat. Physicians almost always wear lab coats over street clothes; occasionally they wear scrubs. Floors are gleaming, equipment is clean and much of it appears new.

Surrounding the central island area, there are eleven private examination rooms off to one side, an open ward with four more beds behind the islands, and four three-sided walled areas for trauma or acute medical patients. In the trauma rooms there appear to be great quantities of equipment: for example, there were four separate IVAC infusion control devices in one room alone. Toward the "front" of the department, where the ambulance entrance and walk-in triage and registration areas are, are two small utility rooms. The triage desk is a small desk just inside the entrance, softly lit, across which the nurse can reach easily to feel a pulse or assess a wound. If more than one patient at a time presents for triage, their names are written on a clipboard and they take a seat in the lobby and wait to be called up by the nurse.

There is a quiet staff lounge just off the ambulance entrance. The door to the staff lounge is left open. There are microwave, coffeepot, refrigerator, sink, mirror, table, desk, couch and several chairs. A large rack holds about 25 colorful assorted mugs. Staff bathrooms were nearby, adjacent to the neighboring intensive care unit/coronary care unit and operating rooms.

Overall, it is usually remarkably quiet. People are talking with each other as the work is carried out, but in general the noise level is subdued. One black female patient's voice is remarked upon by a physician who asks what that patient needs besides (makes gesture indicating corking mouth). No one shouts here. Most patients are seen and treated in the private rooms, which have doors that can be closed. The critical/ trauma rooms have long, wide curtains that can be pulled across for patient privacy.

Nurses seem to have a less assertive role here than at Site B, City Hospital. The nurses tend to initiate fewer procedures before the physician sees the patient, perhaps partly because waiting times seem to be shorter in most cases. There seem to be about 6-8 RNs at all times plus a clerk and a technician who runs errands, cleans gurneys, and helps the transportation team with admissions. There are centralized transportation services for admissions and special studies elsewhere in the hospital, and X-Ray comes and gets patients for studies and returns them when the studies are completed.

The lobby area is divided into three separate areas, each like a medium-sized living room, with soft lighting, a television, carpeting, and comfortable chairs. There are several magazines on the reading tables. I ask the triage nurse if there is a xerox machine to make a few copies of my information sheet. She directs me to one in an open alcove just off the lobby, across the hall. It is left unlocked and accessible to anyone who happens by.

When I take a coffee break, I am directed just down the outside hall to an atrium area that soars five stories to a glass ceiling. It houses an upscale coffee and luncheon takeout, a gift shop, a bookstore, a number of small tables and chairs, live plants and a fountain. Everything is spotless.

City Hospital

Site B, the primary data collection site, is a public hospital located in a major metropolitan area. City Hospital, as I have chosen to call it, is also a trauma center and a university-affiliated teaching hospital, with residency programs in a number of specialties.

City Hospital is also located in an inner-city, relatively poor neighborhood. Its emergency department has approximately 70,000 visits per year. The payer mix is, not surprisingly, quite different for City Hospital: approximately 28% of the ED patients were covered by Medicaid or had Medicaid pending; 55% were uninsured or self-pay; 9% had Medicare coverage, and only 6% had private insurance. The remaining patients were employee health patients, prisoners or other categories totalling less than 1% each. Minority and ethnic groups are well-represented in the patient populations of both facilities, particularly City Hospital.

Descriptive Notes.

City Hospital's ED is much larger and more complexly designed than that of Our Lady Hospital, and therefore it requires a more extensive description. Patients enter either by ambulance or by walking up to the triage counter, a desk about 12 feet in length with a sliding plexiglass window between the triage nurses and the patients. Walk-in patients line up in front of the plexiglass and talk to the nurse one at a time about what their problems are. Because the registration enclosure, another long, plexiglass enclosed work area, is directly across from the triage counter, there is no room for the line to extend out perpendicularly from triage, so patients line up leaning along the counter in front of the nurses and are close to each other as they get up to the window where the nurses check them in, necessitating a loss of privacy. Sitting behind the triage desk it is a bit discomforting to me, with patients lining up and looking through from the other side of the glass, as though the nurses were zoo animals, but that does not quite capture the relationship here.

After being seen by the nurse, providing the nurse does not decide to take the patient "right back" to the treatment areas, the patient is given his or her papers and told to take them across to the opposite registration counter. There, the papers are taken and filed according to the acuity classification by the nurse and the time of arrival, and the patients are told to go sit down and await being called up to register. Ambulances arrive from the double doors adjacent to the registration area. When more than one ambulance arrives at the same time, the patients are all brought in through the outer doors, through double blue metal doors which are opened with a secret code, and into the narrow hall beside the triage desk. There may be three or more stretchers alongside one another at a time in this hallway as the triage nurses sort out who is the sickest. The patients, meanwhile, look around at one another curiously, if they are conscious.

An open area to the side of the outside ambulance entrance is known by the staff as the "gurney garage," or "GG" for short. A security guard who is actually a city policeman is on duty by the inner door, which is locked. Patients who are "parked" in the GG, awaiting registration or awaiting being taken into a treatment area, are monitored by the triage nurses. These are often patients who are not safely ambulatory, particularly those who are assessed as drunk. On the wall of the GG are small green plastic squares numbered 1-5 over the head of each gurney. Above those is a larger blue sign with white letters that says: "Do not take gurneys from this area," a smaller "no smoking" sign, and a fire alarm. There is also a clock on the wall nearby.

The inner portion of the ED is divided into three treatment areas, an observation area, a laboratory, and a main desk area:

The *medical ward* is a long, open ward with short yellow curtains hanging between every two gurneys; there are spaces for about twelve patients, but when it gets busy, there are often more gurneys than there are spaces, and then stretchers are either crammed in more closely together or left in the walking area between the gurneys and the opposite wall. There is a small table and several chairs where both nurses and doctors sit to do paperwork or use the telephone. Patients in this ward are considered non-trauma and non-immediately life-threatening cases, although sometimes very ill. Patient bathrooms are located at each end of the ward.

The *Trauma Side* is an L-shaped hallway with three large trauma rooms and several smaller examination rooms opening off the hall. On one side of the L is a small desk, again shared by doctors and nurses. Patients are also often seen in the hallways of this ward, particularly if they have minor extremity injuries, but when it is very busy, it is not uncommon to see patient gurneys lining the halls as well as filling all the rooms, plus ambulatory trauma patients on chairs in the hall.

The *Ambulatory Side* is a clinic-type area where ambulatory patients with relatively minor illnesses are seen. It is a roughly H-shaped unit, with the common work desk forming the crosspiece of the H and examination rooms opening off two hallways. The staff and patient bathroom is located here; it is often missing toilet paper, paper towels, or both, apparently stolen by someone, since there is no cardboard roll remaining.

The *Observation Ward* is located between the Medical Ward and the Trauma Side and accepts patients from both areas who are either waiting for test results, admission, or discharge. Its purpose is to decompress the other areas. This is an open ward with a capacity of about eight patients. Curtains divide every two gurneys.

In the center of the inner ED, between the trauma and ambulatory treatment areas, is the charge nurse/clerk central desk. This is a desk approximately 15-20 feet long, with telephones and computers. It is opposite the "stat" laboratory. Charts from registration are brought and placed on the counter in front of the clerk, who further puts them together and logs them. Then usually the charge nurse or a volunteer takes the charts and distributes them to the treatment areas designated by the triage nurse. The clerk also answers the phone. Blood going to the upstairs lab is brought in plastic bags to this same counter and the clerk gets volunteers to deliver it. Patients also come to this counter to ask for bus tokens and to get their prescriptions tubed to the pharmacy during certain hours.

Behind the charge nurse/clerk central desk is the staff lounge, a small room about 20' by 20' with a table, 4-5 chairs, a stained couch, a dozen beat up and rusty gray lockers against one wall, a refrigerator, microwave oven, and a sink. There is also a coffeemaker on a small table. A tiny mail room holds slots for all staff, coat hooks and a few more lockers. It is piled with coats, jackets, bags, an extra EKG machine. A noisy fan hums constantly in the ceiling. Bulletin boards line the walls with personal letters, staff and union notices, hospital announcements, a calendar, schedules, etc. There is also an erasable marker board on which various messages and announcements are written. One reads, "Please, please don't leave our gurneys in the hall outside... People are sneaking off with them." The department just got 28 new "state of the art" gurneys after experiencing a shortage so bad that on more than one night they had to lie trauma patients on the floor.

The nurses and doctors all wear different clothing. Some wear white jeans and scrub tops, others white jeans and t- shirts or sweatshirts, some wear scrub pants with sweaters or sweatshirts, some solid scrubs, some white pants or skirts. Some of the doctors wear lab coats, but many wear scrubs, or occasionally jeans and scrub tops. One morning when I arrived all the night nurses were wearing assorted cloth hats made of colorful fabrics. They said it was "hat night." Nametags, if worn, commonly list only the nurse's first name, followed by "RN, Emergency." Some of the nurses have taken tape and covered the last name on their tags. This is also true for many of the doctors. However, many of the nametags do not even list the last name at all.

Nurses and doctors do not have separate work and socialization spaces here as they did at Site A. Here, in each work area, the nurses and doctors share a common desk, chairs, and space and work in a very open unit. I speculate that this may be a contributing or at least enabling factor related to what I perceive to be a much more egalitarian relationship among nurses and doctors here. The nurses have a powerful role and are able to refuse, for example, to accept a patient in the observation ward if they deem that it is too busy. They also control the flow of the "bag lunches" that are sometimes given to patients (Malone, in progress [1]).

Nurses and doctors tend to talk about patients to each other in front of the patients as though the patients could not hear them, there being no private place in which to talk, but their relatively egalitarian relationship does not extend to the patients, who are often not addressed at all except when something is about to be done to them or during the initial examination. At least once a shift, a large clot of doctors passes through the ER and stops at the foot of each patient's gurney in turn, whereupon the resident caring for that patient details "the case" for his/her attending and the others. The patient is not invited to be part of this discussion. When I ask nurses about possible candidates for my study, they readily say, in full voice, "*he's* one," gesturing to a patient nearby, or "*she* just came in this morning and now she's back again." I feel an urge to shush them.

Off the area by the main desk, opening off the corridor through which patients enter the trauma side, is the "family room," the place where families of critical patients being resuscitated wait to speak with the doctors or the charge nurse about their family member's condition. Its heavy blue metal door is usually kept locked. (I am told this is because people made off with the furnishings.) I was able to use it on a few occasions for interviews when the department was not busy. The room is about 20' by 20', painted cream, carpeted with a flat grey-maroon carpet. Nine stained, somewhat worn chairs are placed around the room with their backs against the wall. The chairs are attached to each other and to the tables, so they are not easily moved. There is an orange formica-topped counter with a sink, and above, a clock on the wall stopped at 5:37. There is a black telephone, an artificial plant, an empty box of kleenex, a single magazine, and, today, a partially deflated cluster of colored balloons on one chair. A red sign on the wall says "No smoking, eating, drinking in this room." There are two lighting options: bright overhead fluorescent lighting or very soft wall lighting from two fixtures on one side of the room.

The overhead light seems harsh, makes the room appear even starker. The wall lights, in contrast, are too dim; the room appears gloomy when they are on alone. There are no windows. There is a block of wood screwed into the wall about one foot from the ceiling on the wall opposite the door. On it, in pencil, someone has scrawled "TV".

The lobby (also see sample fieldnotes from lobby observations, Appendix G) is a large room about 30 feet square, with a television set in one corner that always seems to be on at full volume. Rows of black metal chairs line the walls and a small cluster of them sit in the center. There is a drinking fountain. The walls are institutional gray, the windows high in the back wall. The area is incredibly noisy, with the TV, people talking to one another, a microphone system through which clerks call patients to complete their registrations and nurses call patients to triage or to be taken back to be seen. There is near-constant activity throughout the department and all the areas tend to be noisy, since there are only a few private examination rooms with doors and these are customarily kept propped open so patients can be observed. The effect is to obliterate privacy for everyone, staff as well as patients.

Differences Between Sites

Site A, Our Lady Hospital, was, as noted, a private, nonprofit hospital and the ED saw about half the patients seen by City Hospital, the public facility. Other differences between the sites became apparent during data collection. Site A, for example, while having approximately half the visits of Site B per year, had proportionately fewer heavy user patients. A look at the top 100 patients in terms of number of ED visits in the calendar year 1994 showed that at Site A, those patients made a total of 1488 visits, ranging from 7-37 visits per patient. However, there were only 47 who visited more than ten times in the year and only two who visited more than 20 times. At site B, the top 100 patients during the one year from 6/92 through 5/93 made a total of 2318 visits, and ranged from 17-55 visits apiece. All 100 patients visited more than ten times and 52 patients visited more than 20 times. This meant that not only did Site A have many fewer heavy ED users, but those patients also visited less frequently. Yet the issues which came up in patient and provider interviews were remarkably similar, suggesting that it is not merely volume of heavy ED users that is involved in understandings of the problem.

In terms of practice, the patient flow was much faster at Site A for the routine patient, with most patients registered, seen and treated in two hours or less and many in far less time. At Site B, it was not uncommon for patients to wait two hours after registering before being called back to be seen by the doctor, and frequently patients waited much longer. Once called back, patients might not be discharged until five to eight hours later, depending upon their status. For trauma patients, however, patient flow from admission to disposition appeared to be about the same or possibly a little faster at Site B.

Patients at Site B received more nonmedical services, such as showers for body lice, bag lunches, clean dry clothing, and recognition by the staff. Rooms at Site A were all private and most had doors that could be closed. At Site B many patients were clustered in large open wards or parked in halls on chairs or gurneys. Patients at Site A were less likely to be homeless.

Participants

Participant Characteristics: Patients

General.

Forty-six patients participated in taped interviews; there were nine refusals (slightly over 16% of those approached for interviews, for an overall response rate of almost 84%). Five patients were interviewed more than once, for a total of 52 patient interviews. Of the 46 who participated, 16 (35%) were female and 30 (65%) were male. One person declined to be taped but expressed interest in being interviewed; I took detailed handwritten notes of this interview. No one else objected to taping.

Ethnicity.

The patient sample was approximately 47% minority ethnicity, with 24 (52%) Caucasians, 18 (39%) African Americans, 3 (6%) Latino(a)s, and 1 (2%) Native American. There were no Asian or Pacific Islander patient participants, nor were any Asian patients referred as possible participants, a finding I find worthy of further study, particularly since the overall hospital patient population at Site B is at least 15% Asian/Pacific Islander. Twenty-five of the interviews were conducted at Site A and 27 were conducted at Site B.

Age; Exclusions.

Sixty-five percent of the patients were between 30 and 60 years of age (n=30). The age breakdown of the patient sample was as follows: 18-29 years, n=8 (17%); 30-39 years, n=9 (19%); 40-49 years, n=14 (30%); 50-59 years, n=7 (15%); 60-69 years, n=4 (9%), and 70 and over, n=4 (9%). Minors were excluded since prior research suggests children do not represent a significant portion of this population and since their ability to choose whether or not to utilize ED services is limited. Also excluded from the patient interview sample were prisoners in custody, other institutionalized individuals, persons with life-threatening or significantly unstable conditions, and persons unable to speak or understand English.

Socioeconomic Status.

Unfortunately, due to several reasons including the constraints of doing research within a constantly changing site such as an ED, the primary foci of interviews, and the nature of the population interviewed, income/insurance data was not obtained on all patient participants. No information was obtained from 11 participants (24%); 7 patients (15%) said they were on welfare/General Assistance; 9 patients (20%) stated they had no insurance of any kind or stated they were homeless and did not provide further information; 16 patients (35%) said they were on disability/SSI; and 3 patients (7%) were covered by private insurance [percentages rounded]. The average monthly income of patients receiving disability payments was approximately $600; welfare/General Assistance payments varied by state but averaged approximately $380 monthly. Given that this yields a total of at least 32 patients (70%) who were on public assistance or were homeless, and given that at least four of the patients on whom specific insurance information was not obtained were severely mentally ill, it is clear that the sample as a whole conforms with trends in previous research on this population in that the sample is a group of the very poor.

Social Surroundings.

A majority of the patients with whom I spoke at any length either had no family or were estranged in some way from family; at least one quarter of them were homeless, although not always on a continuous basis. Even those who had at least part-time homes of some sort often lived alone or in abusive social situations.

Chronic Illness.

The majority of the patients suffered from debilitating chronic medical problems which made dealing with poverty and isolation even more difficult. Six (13%) of those I spoke with were obviously mentally ill; seventeen (37%) had now or formerly had problems with chronic alcoholism, drug dependency, or a combination of these; and eleven (24%) had other chronic conditions such as asthma or other chronic lung diseases, seizure disorders not clearly related to alcohol, and/or chronic pain. In at least two cases, spousal abuse played a role in the patients' lives. An interesting finding of this study was that at least five patients whom providers referred as heavy ED users did not meet my minimal criteria of four visits per year. These patients were all viewed by providers as being in the ED with "illegitimate" complaints (see Chapter Six).

Participant Characteristics: Providers

General.

Thirty health care providers both participated in group interviews and provided information on their years of experience; approximately 5-10 other providers participated but did not provide this information. Although almost all the providers who participated in group interviews were registered nurses, a few physicians, medical students, and other staff members also participated; in the interest of protecting their confidentiality, I refer to them here only as "providers."

Experience, Gender, Ethnicity.

The providers constituted a highly experienced group, averaging over 15 years of experience in practice (range 5-35 years, median 10.5 years) and over 11 years in ED practice (range 2-30 years, median 9 years). Eight providers (26%) were male. The average age of the provider group was 39. The provider group was overwhelmingly Caucasian, reflecting the composition of the staffs of both EDs, which likewise was predominately Caucasian and female; only three providers were of minority ethnicity.

Procedures

Entree into the Research Settings

CHR Approval.

ED nurse managers at both institutions were the initial point of entry. I contacted each nurse manager by telephone, introduced myself, and arranged to meet with them in person to discuss the study and answer questions. At Our Lady Hospital, I also met personally with the physician director of the department and with the executive secretary for the institutional review board (IRB). Letters of preliminary approval for the conduct of the research were obtained from both nurse managers and included in the application for UCSF Committee on Human Research (CHR) approval. CHR approval was obtained via expedited review.

Institutional approval.

Following UCSF CHR approval, I sought and obtained approval to conduct the study from the Our Lady Hospital IRB, which required that I have a medical staff sponsor. The ED physician director agreed to act as my hospital sponsor. I also presented the study to the City Hospital Nursing Research Committee, which granted formal approval.

Department Entree

At each of the hospitals, I attended department staff meetings, introduced myself as an emergency nurse doing research on "frequent visitors" (considered a less potentially judgmental term for heavy ED users), and presented the study to those in attendance. An information sheet about the study was distributed to those present, posted on department bulletin boards and placed in the unit communication book (see Appendix B). Verbal consent to have an observer present was obtained. Verbal consent is considered to be sufficient for ethnographic observations because observations and the conversations or brief interviews are everyday events and general opinions. No intervention is involved. Nurses and physicians both expressed great interest in the study.

Data Collection

Participant Observation.

Fieldwork at Site A was completed over a period extending from December, 1993 to March, 1994. This was followed by fieldwork at Site B, the primary data collection site, which was carried out from April, 1994 through December, 1994. Data from Site A were used to refine the observational and interview approaches at Site B.

Fieldwork entailed observing in and around the EDs, talking with patients, staff, and others and simply watching the activities and interactions taking place in the various work areas. Examples of fieldwork activities included following various patients from triage to discharge, observing at the different work areas in both EDs, sitting overnight in the waiting room of Site B, riding along with the city detoxification unit van and spending a day at the detoxification center in one city, among other activities. I observed during all shifts and at various times during the week, but as analysis progressed I focused my observations on weekends, because providers suggested heavy ED users were more likely to come in on those days. The hours spent in observation varied from as little as two hours to fourteen hours. Most days, I spent between four and eight hours in the setting.

I especially tried to pay attention to conversations and interactions between staff members about "frequent visitors" and between staff and patients who were "frequent visitors." Fieldwork foci developed out of the emerging concerns revealed by concurrent data analysis; for example, the decision to spend one or more nights in the hospital lobby arose from interview and fieldnote data in which the lobby was mentioned several times. Fieldwork notes were made on site in as unobtrusive a manner as possible and written up after each day's observations. Field notes include observational notes, basic descriptions without much interpretation; theoretical notes, suggesting emerging coding categories, etc.; methodological notes; and personal notes, about the experience of doing the research itself (Schatzman & Strauss, 1973; Wilson, 1985), although I did not always draw clear distinctions between these in writing them. I wore a white lab coat over street clothes and a name tag identifying me as a researcher at all times while within the ED; for my lobby observations, during which I did no interviewing, I wore street clothing in order to observe unobtrusively.

Brief Patient Interviews.

After an initial observation-only period of several days at each site during which I tried to note routines, flow, and other contextual details and establish rapport with staff, nurses who expressed willingness to participate were asked to advise me when they recognized a "frequent visitor." This method of obtaining a patient sample was specifically chosen for several reasons:

First, in teaching hospitals, nurses are the only group of providers consistently present in the ED over periods of several years; resident physicians and others are constantly rotating through various clinical areas and thus do not have the opportunity to get to know these patients over time, as nurses do.

Second, data is not routinely collected that would enable a researcher to know readily whether or not a patient is a frequent visitor. Unless *every* patient's medical record was examined, an unworkable expectation for a single researcher in a setting where 300 patients a day may be presenting for care, there is no other immediate and practical way to identify the heavy user patient. Although the computer data systems of both hospitals have data about last and/or recent visits available to registration clerks in the ED, I learned that episodes of ED care were dropped from the system once bills for the visits had been paid or written off as uncollected debt, so this was unreliable in assessing heavy use.

Third, this method was chosen to help illuminate multiple aspects of the problem of heavy ED users, including its social construction and the ways in which that social construction plays out in clinical and policy decisionmaking. It was of specific research interest to learn something about how certain patients or types of patients are viewed by providers as belonging to this category, while others are not. This aspect of the research proved extremely informative toward the analysis developed here.

Once a patient was identified as a heavy ED user, I approached, explained my study, and asked the patient if he or she would be willing to talk with me. The general format for obtaining verbal consent is detailed in Appendix A. In lieu of written consent, which was waived in the interest of providing special protection for patient confidentiality, patients were given an information sheet about the study (see Appendix C).

The majority of the Site A interviews, though not all, were brief; they were used to refine interview technique and questions as analysis proceeded. These interviews tended to be more formally question-answer in structure, with less narrative elaboration; thus these brief interviews were of less analytic interest as the research progressed. However, these brief interviews were invaluable in helping me understand the crucial importance of cultivating patience and relaxed silences in establishing a trustful research relationship with this group of patients. Once I was able to be more relaxed about whether or not I accomplished my preestablished agenda of questions, analytically rich narratives began to emerge. The interviews were concluded when either the patient chose to stop, other events precluded further conversation, or when further questions seemed unlikely to produce analytically interesting responses.

In-Depth Interviews.

These narratives form the heart of the project. The in-depth interviews, which were guided by the concerns of participants, lasted from 45 minutes to, in one instance, almost four hours. Again, the study was explained, verbal consent was obtained, and the information sheet was offered. These interviews were conducted in a variety of settings, including family room areas, lobbies, the "GG," and the ED treatment areas, depending on where the patient was in the process of being seen and how busy the department was at the time.

The interviews began with one or more of the preliminary questions outlined in an interview guide I developed before beginning the study (see Appendix E). These questions were intentionally written to be largely open-ended, encouraging participants into narrative forms of response rather than abbreviated replies. Some of the questions required modification or simplification; for example, a question about whether patients thought it was different to come to the ED as an "experienced" patient, intended to elicit information about their practical understanding of being a heavy ED user, drew many puzzled responses until I rephrased it as follows: 'If you had a buddy that needed to come here, what would you tell them?' That question drew detailed responses centered around practical strategies for coping with long waiting times and the organizational structure of the ED itself, strategies which had been learned in the process of being a frequent ED visitor.

When participants began a story, I attempted to not interrupt them until they finished, unless an interruption seemed essential to clarifying a part of the story itself. Once the story was finished, I would make some brief comment and then ask if they had had any other experiences like that, or any different experiences. Often participants would volunteer these contrasting cases without further probing on my part. I also tried to be attentive to embodied (nonverbal) responses, noticing how participants leaned forward, made more direct eye contact, became more animated or withdrawn while talking about certain topics or telling certain stories. For example, one interview with a man who described himself as "homeless" plodded along with monosyllabic responses to my questions until I asked him about getting by "on the street." He shifted his body up in bed, made direct eye contact, and began to talk in a much more animated and detailed way about "hustling"--collecting cans, panhandling, doing odd jobs--and how he saw it as a challenge.

Once it became clear to participants that I did not have a rigid research agenda, but was genuinely interested in hearing about their lives, they spoke eloquently and at length as they told their stories. Four of these participants were interviewed on two separate occasions and one participant was interviewed three times.

The interviews usually were concluded by the patient participants, who would say, "Okay, that's enough talking" or the equivalent. On a few occasions, I terminated an interview when it seemed apparent that the same issues were being revisited again and again without significantly new findings. Once I terminated the interview, even though the participant was still talking eagerly, because it had extended far past the time I had estimated in explaining the study, and I felt it would be a possible abuse of the patient's willingness to participate to continue.

Medical Records Review.

Medical records were reviewed to confirm or disconfirm heavy ED use on 30 patients; more extensive review of records was carried out on the charts of eight patients. Consistent with the review of the literature, a rather liberal definition of heavy ED use of four or more visits per year was used. In keeping with the primary aims of the study, the medical record was read primarily as biography (Waitzkin, 1989), focusing on patterns in the way the patient's story was told through the medical record and the ways, for example, instructions given the patient were congruent or incongruent with the patient's actual possibilities in the context of his/her life as revealed by interview data. Dates and times of ED visits for at least a one-year period were noted, as were notations that the patient "left without being seen" by a physician.

Group Interviews.

Following the observations and patient interviews, a series of small group interviews with nurses was conducted, eliciting narrative accounts of concerns and practices related to heavy ED users. The interviews at both sites were conducted in the staff lounge area, a setting conducive to stimulating the normal conversations about patients that nurses and other staff carry on in such a place. I posted notices and told the charge nurses to let their staff know that I wanted to hear stories about "frequent flyer" patients, as I had learned through experience and fieldwork they are commonly called in ED vernacular. I again explained the study's aims and my aim in doing the group interviews with nurses and written consent was obtained using an approved consent form (See Appendix D).

These interviews were very informal. Benner, Tanner, and Chesla's (1992) work with groups of nurses showed that group interviews of this type have advantages over individual interviews in that the natural group process of sharing stories with peers--as opposed to giving answers to an interviewer's direct questions--tends to facilitate greater recall of details meaningful to participants and stimulates sharing of contrasting cases. This proved true in my work as well, as nurses and other providers listened to each other's stories and volunteered or interjected their own experiences. These interviews proved rich data sources. The group interviews lasted approximately 2-3 hours each, with several "shifts" of nurses rotating through as their lunch schedules permitted. In a few cases, nurses who had heard about the study made the effort to come in on their days off or stayed late after work to participate.

I began each interview session by explaining that I wanted to hear about nurses' experiences with frequent visitor patients. An interview guide (see Appendix F) was used to start the conversation; once the staff began talking about these patients, few probes were needed to keep the flow of discussion going, although I occasionally had to bring the focus back to "frequent flyers" if other kinds of conversation began to dominate (Morgan, 1988). The interviews were audiotaped and the tapes transcribed verbatim.

Withdrawal from the Field

Leaving the field, as S. J. Taylor (1991) observes, involves both knowing when to stop collecting data and how to manage the personal act of leave-taking from those with whom the researcher has established trusting relationships. Regarding the first, Taylor says that the decision must be arbitrary: "A study is done when you have gained an understanding of the setting or slice of social life that you set out to study" (p. 241).

Yet such an understanding can never be complete, definitive, final; thus, Taylor continues, "the question to ask is not 'when is the study finished?' but 'when does the fieldwork yield diminishing returns?' " (p. 242). Some field researchers refer to this as saturation, a point at which continued observation does not seem to produce additional understanding. In this study, I felt that I had probably reached saturation in ED fieldwork, but if time had permitted I would have preferred to do additional off-site fieldwork. However, given the time and funding constraints, this was simply not possible.

The relationship aspects of leaving the field are perhaps more complex. I exited from the fieldwork setting rather gradually, increasing the intervals between my visits, and advised staff that I would be returning for group interviews later. At the completion of group interviews, I thanked staff for their participation and reminded them that I would be returning to present findings of the study.

The point of interpretive inquiry is not merely to increase the understanding of the researcher, or to result in a published work, but to open up the possibility of new views on the part of the participants as well. Packer (1985) compares the difference between a traditional rationalist or empiricist explanation and an interpretive account to the difference between a map of a city and a portrayal of the city by someone who lives there:

> The professional mapmaker must regard a city as merely a juxtaposition of physical objects. For its inhabitants, it is a system of possibilities and resources, frustrations and obstacles, and two people will find both commonalities and differences in their accounts of it (p. 1092).

Documentation

Fieldnotes

Fieldnotes were handwritten in a small notebook I carried in my pocket during observation periods. I personally transcribed all fieldnotes into the computer, usually adding additional comments during the transcription process. These were set apart from the original contemporaneous on-site notes by brackets. Fieldnotes were more copious in the beginning of the study as I sought descriptive detail. As the work progressed, I focused on looking for confirming or disconfirming evidence to compare with and augment my understanding. I made a special effort to document conversations and interactions between heavy user patients and staff.

Taping and Transcription

All of the interviews were audiotaped, with the exception of one patient participant who did not wish to be recorded. I used a small cassette tape recorder and either a flat microphone or a wand-type microphone, with which I found I had better sound quality. I personally transcribed approximately one-half of the interviews, using a transcription machine with foot-controlled replay device, until funding for transcription was assured. Although enormously time-consuming, this proved useful in that it made me intensely familiar with my data set so that it was easy for me to remember where a particular issue had come up in the data. It also was helpful in analysis, when I could often recall the tone or emphasis on a particular word or phrase without having to re-listen to the tape.

Once funding was obtained, the remainder of the transcription, including most of the long patient interviews and all of the provider group interviews, were transcribed verbatim by a professional transcriptionist onto computer diskette. The transcriptionist was instructed to include marginal elements such as pauses, "uhs," coughs, laughter, and the like and to avoid correcting grammar. If words or phrases were unclear, this was noted as (inaudible). Upon receiving the transcription back, I re-listened to each interview and made corrections on the transcription, based on my memory of the interview and my re-hearing of the tapes. (This proved a sometimes amusing process; for example, one reference to "locus of control" was transcribed as "locusts of control," truly a fearsome image.)

Many researchers have commented on the elusiveness of assuring oneself of a truly "verbatim" text (Atkinson, 1992; Waitzkin, 1990, 1991). Aside from the common problem of simply mishearing words, the interpretation of emphasis, the attention to pauses and marginal elements, and decisions of how much detail to include about the speed, pitch, cadence, and so forth of recorded speech are all elements of transcription which can vary depending upon who does the transcribing and checking. Researchers engaged in analyzing the structures of language often require immensely detailed transcripts. These can be difficult for the average reader to access and I felt the additional detail, itself always still the product of an often implicit interpretive decision, would not be of great value for the type of analysis planned.

In the report of findings, therefore, transcribed sections of text appear as close to verbatim as possible. When there were interruptions or asides that were not related to the narrative, edited portions of text are marked with ellipses (...). When names or other identifying information came up in the text, as they sometimes did in both group and individual interviews, they were replaced with a substitute in brackets. My intention in deciding what to include and what to leave out was to be as true as possible to the speakers and their stories, interrupting their voices as little as possible.

Memos

Memos were prepared to help document the "trail" through the data, to prod my memory of certain events or ideas which might later prove analytically important, and to chart my course as a researcher. These informal notes, kept in a file folder as well as in a computer file, were also used to help prepare progress memos which were sent to the members of my dissertation committee for review.

Data Management

All transcribed fieldnotes, interviews, medical records data, memos, and interpretive notes were kept in separate files on my personal computer, backed up by diskettes and by a tape backup. I also kept printed copies of all these, plus the tapes and other research-related materials, in a locked file cabinet. Following Lofland's (1971) advice, I kept one chronologically organized complete set of data and opened new files for emerging thematic categories, possible articles-in-progress, and process notes on carrying out the research and lessons learned. Using the word processing program Microsoft Word for Windows, I was able to open several windows at a time and copy or cut and move data into files as needed. The "find" feature proved useful when I remembered a particular word or phrase from a portion of text but was not sure where in the document it occurred. (I had anticipated possibly using the Ethnograph computer program in data analysis, but after consultation with other researchers familiar with the program, and after becoming comfortable with working with several windows open at once, I decided the investment of time required to learn the new program was not justified for this project.)

Data Analysis

In an interpretive ethnographic study, data analysis begins with the first outlining of initial lines of inquiry and continues through the last writing-up of findings. I anticipated examining my data for stories linked with relationships, dimensions of the problem of heavy users, and narrative themes; I did so, but not in the neat and sequential way I had imagined. It is difficult to be explicit about data analysis in this type of work, since so many of the insights that prove most fruitful in analysis begin as hunches, nagging questions, or even less explicit urges of one sort or another, but several processes were most helpful. First-level data analysis in this study was carried out using three interrelated interpretive strategies: paradigm cases, thematic analysis, and analysis of exemplars (Benner, 1994; Leonard, 1994).

Paradigm Cases

The word paradigm has become so laden with theoretical baggage that I am almost reluctant to use it, but I base my use of the term on Benner's (1984, 1994a) very fruitful use of such cases, broadly conceived as *strong instances* of something. According to Benner,

> paradigm cases are the most usual point of entering the dialogue with the text. Paradigm cases are strong instances of concerns or ways of being in the world, doing a practice, or taking up a project. To identify a paradigm case does not require the researcher to identify in advance what he or she is "looking for" (1994a, p. 113).

I began by taking as a case Matthew, one of the patient participants whom I knew was regarded by providers as an incorrigible alcoholic, a patient whose name was always the first to be mentioned when I asked about "frequent visitors" to the ED. I carefully read all my interview and fieldnote data relating to his case (medical records data was also incorporated into several paradigm cases). I took as my task trying to open myself to the underlying concerns embedded in the kinds of extended narratives he shared with me. I sought to identify the links between these stories from Matthew's point of view and from my own, moving back and forth from the whole interview text to the several long narrative segments that stood out for me.

My objective was to grasp the "story of the stories" Matthew told, coming closer to an insider's account of his lived experience. Initially, I struggled to make sense of several very detailed stories that seemed to have no relevance to my research questions. Matthew told me about wrecking a car, nearly drowning, and drinking a whole bottle of whiskey. His life seemed utterly self-destructive and incomprehensible, and he said very little about the ED. But as I carefully reread these stories, and then returned again to the whole interview, other subplots began to emerge: Matthew's troubled relationships with his family, his wishful self-conception as a "strong" man, and his desperate hope for heroic rescue.

Gradually, I came to see that Matthew's drinking constituted a way he sought reassurance that he was worth caring for, a way to express his anger at his family, a way to avert seizures, and a way to test his own limits. His visits to the ED were embodied pleas for the kind of heroic rescue he wanted desperately to be too strong to need. In the context of his life, Matthew's horribly self-destructive behavior had a kind of coherence.

I used the medical records data to flesh out the interpretive account by illustrating how patient behavior was interpreted by providers in the institutional record. Benner (1994a) emphasizes that in developing a paradigm case, one does not assume that the text will be made "rational" or that it will somehow link ideology and practice. Once I had developed Matthew's case, I developed several others and was then able to examine each in light of the others, seeking to articulate the way the practical worlds of the participants were similar or different.

Thematic Analysis

All fieldnotes, interview data, and memos relating to a case--in this study, a heavy user patient or a particular issue--were read several times in order to gain a first grasp of the material. Although I did watch for particular phrases which recurred in the data, I focused on patterns and concerns rather than on particular word choices. I made marginal notations of possible themes, beginning interpretive codes, interesting patterns, and cross-references with other data.

An example of something I noticed early on was the tendency of patient participants to verbally stumble when using the first person singular in a story. It was quite common for patients to stutter ("I--I--I") or to otherwise interrupt themselves or sometimes even hesitantly argue with themselves in ways that indicated uncertainty in articulation. Devault's (1990) wonderful work on the disjuncture between language and women's experience, which I later came across, was helpful in offering a perspective from which to view this phenomenon. Devault suggests that these difficulties of expression can be analytically significant:

> Often, I believe, this halting, hesitant, tentative talk signals the realm of not-quite-articulated experience, where standard vocabulary is inadequate, and where a respondent tries to speak from experience and finds language wanting (1990, p. 103).

As my analysis progressed, this was a helpful insight as I came to see how scarce were these patients' safe possibilities for seeking recognition (see Chapter Eight) and how necessary that recognition is to the maintenance of a self. It was only infrequently that they were given the opportunity to talk about their experiences, and when they did so, it was with some effort. This deepened my understanding of both patients' and providers' experiences, because once I noticed this pattern, I began to notice some similar hesitations and qualifications in nurses' talk about caring. This in turn led to further thinking about the way social discourses are delimiting of experience, and I began to "listen" to the data for the aspects of experience that were *not* given voice.

This initial stage was very difficult for me because I feared getting started on the "wrong foot." Van Manen (1990) warns of the difficulty in discerning "incidental" from "essential" themes and recommends imaginatively asking whether the meaning of a text is fundamentally dependent on a particular theme. As I continued to read the data, particularly the patient interviews, over and over, I began to notice similar themes that recurred in the stories of different participants. The development of several paradigm cases made this cross-case comparison easier. These recurring themes were assumed to be meaningful for the overall analysis as well as for analysis of individual cases.

As these themes emerged, files were opened and segments of data which seemed to represent instances of the theme, or exemplars (see below) were gathered into them. Some themes were discarded as interesting but analytically inessential for answering the questions of this study; for example, the theme of intrastaff control and power issues. Five broad themes--legitimacy, vulnerability, recognition, transformation, and community--were identified as most important. Four of these became the basis for the chapters in which the findings are discussed.

I began with a global plan to write up findings from providers, patients, and medical records in separate chapters, each representing a different perspective. I also struggled for a time to try to develop a "typology" of heavy ED user patients, either on the basis of their medical diagnosis or of some characteristic way of relating to the ED, but I experienced both these processes as trying to cram a square peg into a round hole: they just didn't fit my data, or they risked reifying already inadequate classification systems.

Then one evening, wrestling with this problem, I realized that providers and patients were talking about many of the same themes--safety, vulnerability, trust, recognition, community. I realized suddenly that they needed to talk *to each other*. To keep providers and patients in separate chapters was a replication of the "us-them" dichotomies which characterized their interactions and contributed to misunderstanding and mis- or nonrecognition.

This realization changed my interpretive approach; I began to sketch out a different plan for writing up my findings. I focused on the ways providers and patients each experienced similar situations and cultural conditions and I consciously strove to consider their respective data as a conversation they were having with each other, in which their commonalities and differences were being worked out. Benner and Wrubel's (1989) list of five sources of commonality explored in phenomenology was helpful. These include situation, embodiment, temporality, concerns, and common meanings. I also made a particular effort to read for contrast cases, cases which seemed to share a similar theme but highlighted some distinction.[8]

Analysis of Exemplars

An exemplar, according to Benner (1985, p. 10) is "a strong instance of a particularly meaningful transaction, intention, or capacity." In reading and re-reading my data, I watched for particular narrative accounts that puzzled, disturbed, or intrigued me, trying to ask myself what kind of self-understanding (of the speaker) and understanding of the situation these stories revealed. The assumption under which I worked was that even actions which seem baffling to an "outside" observer have a coherence when understood in the context of the actor's experiences, and thus stories that puzzled me offered a possible way of access into understanding that experience. I read each interview through several

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[8] I am grateful to Patricia Benner for introducing me to the work of Logstrup (1971), whose moral philosophy emphasizes drawing distinctions as a methodology for analysis of ethical questions.

times, noting segments or lines which seemed particularly revealing in the context of the whole interview, paying attention also to the immediately preceding and succeeding sections, which provided the "local" context within which the story emerged. This was very much a cyclical process of moving between the levels of the interview as a whole, the puzzling or compelling smaller stories within them, and the themes and stories of other participants. Once data were collected in thematic files, I read whole files for the "story" they seemed to be telling about the common experiences and differences between participants, further sorting data into subthemes.

Another helpful step was the preparation, after all patient interviews were completed and transcribed, of a summary document listing each interview by code number, its most important points, the demographic data, and notes for follow-up analysis or comparisons. This proved to be a useful reference in quickly locating data and helped me get an overall "picture" of my dataset.

The three analytic processes were not as distinct from one another as this discussion suggests. Instead, throughout the study, there was a movement back and forth from parts of interviews to wholes, from parts of the dataset to the whole, and from the analysis of individual "micro" level practices and understandings to analysis of "macro" processes and understandings.

Second-Level Analysis

I had anticipated that my data would point clearly to particular policy issues involved in the social construction of the problem of heavy use of emergency services, and they did. However, they also pointed to the essential interrelationships of these issues and the segmentation of the problem (Estes, 1984) as in itself partially constitutive of the problem. I was surprised that the issue of chronic illness was so central to the analysis, for example. Chronicity seemed to be a common element in many of the policy issues, leading to questions about our social understanding of dependency and interdependency.

The temptation was to succumb to the social engineering approach I had tentatively planned and assume that each problem or policy issue was solvable, given the right information, resources, and recommendations. As I worked my way through this study, however (or, rather, as I was led by the concerns of participants), I began to see that the most important issues went far deeper than mere program design or resource allocation decisions, important though these were. The critical issues centered around the difficulties of sustaining a lifeworld within the system: finding public space in which to recognize and care for one another. Therefore, while the second-level analysis does address specific policy issues in relation to heavy ED users, its focus is primarily on extending the first-level analysis by pointing to larger questions we need very much to be asking as policy decisions are made in any area.

Methodological Issues

Insider/Outsider Issues

Carrying out research within one's own subculture has both advantages and disadvantages. Kidd (1992) calls attention to the way the familiar may be invisible under such circumstances (see also Field, 1991; Rhodes, 1990). In the phenomenological perspective, however, this is always the case; in fact, in circumstances in which the researcher is an utter "outsider," the relevant concerns of participants may be unintelligible to the researcher for precisely the opposite reason.

Lofland (1971) points out that it can be important to negotiate a role as socially-sanctioned "acceptable incompetent" when doing this sort of research; the researcher wants to be viewed as "someone who has to be taught" in order to hear participants' practical accounts of their world. This can be difficult to manage when, as in this case, the researcher is already known to possess situationally relevant expertise. However, as Lofland also notes, there are settings where conventionally acceptable incompetents are not well tolerated; the ED tends to be such a place because of its dynamic environment and intense pressures. Having the background of clinical practice greatly facilitated entree and staff acceptance.

As Lipson (1984) has pointed out, being a peer has the advantages of "ease of entry, avoidance of disruption of normal group processes, prior knowledge of some relevant research questions, and an enhanced capacity to solicit in-depth data" (p. 349). Lipson also observes that "there are things an informant can express only to an interviewer of similar background" (1991, p. 79). My background understanding of ED practice also enabled me to ask questions about some semi-covert practices that an "outsider" might never know existed; for example, the keeping of a "secret" file on possible drug seekers and otherwise troublesome patients, which I knew from experience exists unofficially in many EDs. Germain (1986) suggests that a nurse ethnographer in a health care setting may capture nuances that would otherwise be missed. I believe that my years of experience as an ED nurse made it less likely that my attention would be captured by the "high drama" of the setting to the exclusion of the mundane, a risk when "outsiders" enter such a highly-charged setting.

However, being an ED "insider" sometimes led me to uncritically assume, based on my practical familiarity with the setting, that I understood what was meant by a story or phrase. Several times as I read over my transcripts, particularly the transcripts of the group interviews with nurses, I reproached myself over not asking the speaker to give another example or to clarify further what a particular term meant. This was also a struggle of learning to be attentive and patient during interviews yet also keep considering what questions might encourage a richer account. Nevertheless, I also know that some of the stories that were shared with me, particularly the stories of morally troubling situations, would simply not have been shared with a non-"insider" researcher.

Establishing my nurse researcher role as separate from a clinical nursing role did not prove to be overly problematic. I wore street clothing and a lab coat with a name tag identifying me as a researcher; this distinguished me physically from the clinical nursing staff, at least as far as they were concerned, and only once or twice did they ask me to help in a clinical capacity. Several patients, however, did ask me to perform nursing duties, such as giving them the bedpan or bringing them food or drink. I usually responded to these requests by explaining to the patient that I was not there in the capacity of a clinical nurse and offering to get "their" nurse for them. Rarely, however, when the staff seemed especially busy and the patient's request was uncomplicated, I simply got the blanket for the patient or raised the head of the bed. On one occasion, I helped a clinical nurse move a patient up in bed. Overall, I made the effort to maintain my researcher role as entirely distinct from my previous clinical role, both as a way to keep from being co-opted into working and away from my research, and also as a way to establish myself in the researcher role, but my practical familiarity with the setting occasionally dictated that small exceptions be permitted.

Power Issues

The link between knowledge and power has been articulated by many social observers, notably Foucault (1980). An inevitable power differential exists in most research situations in that the researcher knows more about participants than they know about her. Differences in race, class, academic status, and overall educational preparation existed between many of my participants and me as researcher. Many research methods also constrict the possibilities for meaningful expression by participants, for example, by allowing only certain questions to be recognized as legitimate and offering only certain choices as responses.

Lather (1986) suggests that the research process itself be considered a way to reduce power inequities. Mishler (1986) argues that the study of narratives and the empowerment of respondents are linked by the assumption that organizing one's experience into narrative form is a way of making one's experiences coherent and

meaningful. In this way, interpretive research offers an emancipatory capacity (Benner, 1990).

Hall, Stevens and Meleis (1994) call attention to the way much research and intervention considers only the movement from societal center to periphery, characterizing marginalized persons as needful of "development." The suggestion that research based in narrative can be emancipatory is not meant to imply this sort of instrumental relationship. Instead, interpretive research suggests that articulating and hearing one's own story as told to an engaged, attentive listener can itself be a source of knowledge (Anderson, 1991). The aim is to remove the silencing aspects of research so that the person can speak in his or her own terms.

In the present study, I made efforts to minimize the power inequities in several ways: by utilizing a relatively unstructured interviewing approach, in which participants were encouraged to tell the stories that were important to them and to tell them in their own words; by efforts to minimize interruptions; by use of natural, everyday language; by judicious self-disclosure when it seemed appropriate; by allowing the participants' own voices to be heard throughout the report of findings; and by trying to be respectful of participants' understandings.

Ethical Issues

Because of the vulnerability of the patient participants, special efforts were made to protect their confidentiality, including the waiver of written consent, thus eliminating the paper trail back to them from the researcher; the careful avoidance of names in transcribing tapes and taking notes; and the altering of potentially identifying details in writing up findings. I had anticipated disclosures of illegal and/or socially stigmatized activities, and these did occur; I tried to listen with an attitude of openness and nonjudgemental attentiveness. That said, I wondered in some cases if patient participants would not have appreciated the option to have their names used, since it is rare and, I believe, personally validating for them to be consulted as authorities. Their voices are so often silenced by larger structural constraints and by their isolation, as noted above.

I also experienced ethical ambiguity[9] in adapting to my role as researcher and delimiting my role as nurse. The moral commitment of being a nurse (Levine, 1989a) includes the imperative to prevent or alleviate suffering, and I was solicited by the stories of my patient participants and keenly aware of their suffering. I sometimes witnessed patients being treated in ways I considered disrespectful of their humanity, and I struggled over the choice between witnessing as researcher and intervening as nurse.

Van Maanen (1988) describes in excruciating detail a situation in which, as novice fieldworker, he found himself the witness of a brutal assault on a man by the police officers with whom he was riding along. He did not intervene, but took detailed notes, which he refused to produce in court when the man later sued the police department for brutality, even though he knew his eyewitness account would prove the man's case. I am not sure that, were I in the same situation he describes, I would or could do the same. But the moral mandate of the sociologist is not the same as that of the nurse. Fortunately, nothing comparable to Van Maanen's experience happened while I was observing. In fact, some of the events I found troubling were probably no different than many I had witnessed in everyday nursing practice, although in everyday practice I felt freer to say something or to step in. As a researcher, I kept silent.

I can justify my silence by saying that my intervention would not have changed the situation and might have made it worse for the patient in some way. It is hard to predict the consequences of actions undertaken when one is engaged in establishing a new role for oneself. I can say that to intervene would have interfered with my ability to carry out the remainder of the research, thus possibly keeping me from being able to complete the work

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[9] Fine (1993) describes ten idealized versions of the ethnographer's role and shows how each may actually be morally ambiguous.

and possibly meaning that those stories I had already heard would go without being heard by a larger audience. But this reasoning, it seems to me, provides a flimsy ethical cover. Probably more honestly, I recognized that to step in as a nurse and moral arbiter would damage my credibility and acceptability as a researcher in that setting and would make it impossible for me to gain access to the concerns that prompted such actions on the part of people who considered themselves caregivers.

None of these seems satisfactory. I remained secretly troubled over this issue for some time, and I cannot say that I have entirely resolved it now. But I gradually came to recognize that some of my tendency to intervene stemmed from a posture of pity for the poor (and thereby inherently subordinate) patients. As I developed the paradigm cases that inform this work, I saw how many of the patients I had regarded as objects of pity were in fact remarkable, resilient, and savvy at surviving in an inhospitable world. Although they were often perceived as unable or even unwilling to care for themselves, they in fact did make efforts to do so, albeit not always successfully or in approved ways. This insight is in no way meant to minimize the suffering experienced by the participants I interviewed; their lives were often painful, brutally harsh, and sometimes foreshortened. But it is to understand that if one is to reframe the role of researcher into a less dominative one, one must let go of stereotypical and distancing images of the researched. Pity objectifies and separates. I had fallen into the modern interpretive version of regarding my participants as poor "natives."

The Researcher Role

I also experienced some ambivalence over my relationships with the nurse participants in my study. On one hand, it was wonderful to feel that my research might potentially make their concerns more visible, and it was clearly very validating for them to find someone interested in their stories. Like the patients in my study, nurses are marginalized within the "medical" world (Roberts, 1983) and, at the clinical level, their expertise is underutilized in policymaking. On the other hand, I sometimes felt vaguely guilty about leaving the clinical role and "finding my way" as a researcher (Fetterman, 1991) and, as data collection proceeded, I sometimes felt unduly judgmental of my former peers.

This came to a head as I began to write on the theme of legitimacy (See Chapter Six). At first, I could only see the interactions between "frequent flyer" patients and providers in "good guy/bad guy" terms, with the patients as the helpless, hapless sufferers and the staff as the cruel or benighted protectors of authoritarian social structures. Benner (1991) calls attention to the way the market perspective on health care encourages this moral oversimplification:

> The recent tendency to view the relationship of the health care provider and the patient as a buying and selling of goods, that is, health care bought and sold as a commodity by free autonomous agents in a free market, constricts the range of moral issues to stories of "bad" salespersons and helpless patients who are subject to the whims of personal gain from profiteering practitioners. One can hold up the ethical practices of the good salesperson, selling needed and worthwhile goods, but the responsibility for choosing wisely in the free marketplace is left to the economic free agent, the "consumer." However, vulnerability or suffering (compromised "consumers") cannot be sensibly introduced into this moral equation (p. 18).

In this stage of analysis, I felt overwhelmed by the enormity of the injustice and incredibly discouraged at the notion of writing a whole dissertation castigating my peers for their insensitivity and blindness. Hirschman (1979) warns that this sort of "gloomy vision" is the first stage in interpretive reflection, and urges researchers not to get stuck there.

Gradually, I came to realize that such a formulation was too pat, too narrow to capture the complex and sometimes contradictory nature of the relationships between providers and "frequent flyers." It left out the moral concerns of nurses, which came through clearly in my data, and it perpetuated the pitying objectification of the patients. It was also a way for me to maintain distance from the knowledge that I, too, had sometimes treated patients as objects or had responded to them in ways that otherwise reduced their humanity. The struggle to overcome this tendency to frame situations in oppositional terms, which I cannot claim to have done completely, was extremely valuable for me in terms of beginning to understand how two very different understandings of the same situation could both be "true," valid, and even, in context, compatible. It also opened a window for me into the way our culture constructs claims to social legitimacy entirely in such oppositional terms and seeks to affix blame rather than to understand difference.

Issues in Writing up the Findings

One difficulty with this method, for the researcher, is finding a place to "stand." Since the philosophical grounding for interpretive ethnography emphasizes that the notion of real "objectivity" is an illusion (at least when applied to the study and interpretation of human beings' behavior by other human beings), the researcher does not have the luxury, as in traditional science, of taking "the view from nowhere" (Nagel,1986). Writing the findings, for me, involved a process of reflection in which I grappled with several interrelated issues: what tense and person to assume in the writing (Young, 1991), what to include and what to leave out, how to refer to patients and providers, how to organize or not organize the findings into a "story of the stories," who was my intended audience, and other issues. I chose to do what seemed right to me in the context of the developing chapters; thus there are, as noted in Chapter Three, some inconsistencies, contradictions, and shifts in tense that may be troubling to some readers. The attempt was to try to present an account that was temporally coherent, accessible to a wide audience, yet true to the concerns of all participants and analytically revealing.

The issue of what to include and what to leave out is a difficult one for any researcher in this tradition, and it is fundamentally an ethical issue as well as a methodological one. The "wide net" of this sort of study means that the researcher is left with enormous quantities of data, and decisions must be made about how to deal with it.

Geertz (1995) asserts that "there is order in it all of some sort, but it is the order of a squall or a street market: nothing metrical" (p. 2). There is some distress, then, in trying to develop an account that at once inheres, in terms of arising from and remaining true to the concerns of participants, and coheres, in terms of being accessible and sensical to others.

The selections of text presented here are a small sample and I cannot claim that I made reductive decisions based on any predetermined, "objective" criteria; I tried to focus on themes that I heard from more than one source, sometimes including contrast cases, but the aim of the whole was to produce an account that, by giving voice to participants, spoke to the problem from multiple perspectives. Thus this is not necessarily a "representative" sample of data in the usual definition of that word. There are, then, some participants in my study whose spoken words do not appear here. Their contribution to this work is no less valued and their influence was substantial.

Another issue concerned the question of how to deal with the race or ethnicity of patient participants. Because many heavy ED users are of minority ethnicity, I was concerned that, given the social tendency to stigmatize and stereotype, including ethnicity in paradigm cases and samples of text might inadvertently increase the "otherness" of such patients for readers, closing off possibilities for understanding. Yet I did not wish to "whitewash" the social fact that many of the people in the lobbies of public hospital EDs are people of color. In order to resolve this issue, I decided to include ethnicity in my demographics and contextual fieldnote data, but left out references to ethnicity in paradigm cases, except when specifically mentioned within interview data and pertinent to the topic of discussion.

I also avoided focusing on medical diagnoses, although these are mentioned throughout. Because the objective of the study was to increase understanding of the phenomenon of heavy ED use, not to delineate the kinds of diagnoses involved, and because medical diagnoses are socially produced, not independent "facts," no effort was made to determine whether or not patients "really" had the illnesses or past medical history they claimed to have, or whether providers "accurately" assessed the symptoms with which patients presented (Zola, 1973, 1975). Instead, the focus was on the taken-for-granted understandings embedded in such contexts and the way those influenced the interactions between providers and patients.

Other Issues

Concurrently with the latter half of my fieldwork and interviews at Site B, an unrelated intervention study focusing on a case management approach with a small sample of heavy ED users was in progress. I met with the researchers associated with this study on several occasions to discuss any potential conflicts and share our preliminary observations. Because sampling for this study was mostly confined to daytime hours during the week, and because I focused my fieldwork on weekends, no conflicts arose. It is, however, possible that there were other patients who might have been referred for my study who, being enrolled in case management, did not after all utilize the ED as heavily as they might have otherwise. None of the patients whom I interviewed mentioned being involved in case management, although one patient had been referred to the case management team but had not followed up.

Evaluating an Interpretive Account

Issues of Methodological Rigor

The issue of rigor in interpretive research is complex and complicated by continuing confusion with quantitative assumptions (Sandelowski, 1986). However, several strategies were utilized to enhance the interpretive validity of the account presented herein. First, multiple data sources were consulted, not, as noted above, to ferret out the one "true" version of events, but to widen the interpretive lens on the phenomena.

Second, portions of raw data, whole paradigm cases, and chapters-in-progress were read and discussed by my biweekly graduate student interpretive research group. Members were asked to read for themes, patterns and exemplars in the initial readings of raw data; as the interpretive account was developed, they were asked to read for interpretive comments that somehow didn't "ring true" or fit with the accompanying text and for the overall coherence of the account. Portions of the emerging findings and raw data were also shared and discussed with two nurses with experience in ED settings; these discussions proved fruitful in terms of moving my thinking along as their questions forced me to articulate often inchoate hunches, assumptions, and links.

Third, careful documentation of how the study was conducted (as presented herein) was maintained, within the limitations of the researcher's ability to be fully explicit about preunderstandings and the progression of analysis, which proceeded in a nonlinear and sometimes intuitive manner.

Portions of the preliminary research findings were presented to a small graduate student seminar. Students were asked to comment on how the interpretive account did or did not open up their understanding of the worlds of heavy ED users. Findings will also be shared with participants at both ED sites. All these strategies proved analytically useful. However, as Sandelowski has noted (1993), "validation is less a technical problem than a deeply theoretical one" (p. 2).

Hall and Stevens (1991) propose criteria for evaluation of feminist studies that are compatible with the philosophical underpinnings of this study. These include:

- dependability, tested by assessing whether similar meanings can be perceived in raw data by other researchers who use similar analytic procedures;
- reflexivity, wherein the researcher considers and documents her location in all aspects of the research;

- credibility, assessed by the ability of participants to recognize themselves in the interpretation;
- rapport, which may be evaluated by the depth and specificity of the information participants share with the researcher;
- coherence, as evidenced by consistency of the whole account with its parts;
- complexity, evidenced by a focus on identifying meaningful differences as well as similarities;
- consensus, in which there is evidence of congruence among behavioral, verbal, and affective elements of observations, interviews, and written records;
- relevance, in which the question asked is whether the study addresses participants' concerns;
- honesty and mutuality, an ethical stance of the researcher in minimizing deception and power differentials;
- naming, in which the researcher attempts to see beyond conventional understandings and the voices of participants are heard in the research account, and
- relationality, in which researchers emphasize the participatory nature of inquiry.

The Circularity of Understanding

If our background understandings set up and influence our inquiry, and if we already know something about what will count as an answer to our question, how can we objectively verify our findings; how can we prove they are true? We cannot, and the reasons for this should by now be clear. We do not require formal theory and objective proofs in order to understand that the sun is shining on our faces or that someone we don't know well is standing too close; interpretive understanding is an understanding of just this practical, everyday sort. A good interpretive account "rings true" in some way and yet also extends our practical grasp. As Packer notes, "causal laws and formal logic characterize our knowledge in the present-at-hand mode, whereas interpretation is an articulation of ready-to-hand practical understanding" (1985, p. 1090). Does this mean we have no way of evaluating an interpretive account? How can we tell if an interpretive ethnography is well done or not?

The so-called "hermeneutic circle," in which the forward arc represents one's preconceptions and background understanding of the problem, and the return arc represents the uncovering of an interpretation that furthers our understanding--which then reframes our understanding and sets up the possibility for further inquiry--is key to evaluating an interpretive ethnographic study such as this one. Packer and Addison (1989b) emphasize that the forward arc of the circle is not mere conjecture, but a practical understanding of the problem with which we--researchers or readers--begin. Evaluation of an interpretive account thus rests on the simple questions of whether this account furthers our understanding of the phenomenon, whether it answers our concern, and whether it is recognizable while revealing something we did not explicitly realize before. This is why

> the circularity of understanding and interpretation is not vicious. If our inquiry is shaped and motivated by a practical concern or difficulty, and if as a consequence of interpretation we uncover a solution to that difficulty, it is not the case that we have found only what we read into things. The truth of an account will be suited to the perspective adopted in the inquiry, but this is not a vicious circularity, it is precisely what we want. It does imply that we have to be careful to adopt an appropriate perspective and become aware of what our practical concern is, but this is only as it should be. A true interpretive account...is one that furthers our concerns (Packer & Addison, 1989, p. 279).

On this view, then, it is the attempt to fit human sciences research into rational-empirical scientific categories that makes some researchers feel a need to find "qualitative" counterparts to the "quantitative" evaluations of validity, reliability, and generalizability. Research grounded in the phenomenological tradition challenges those categories and challenges those who judge research findings to trust their concerns and their shared experiences of the world (Lincoln, 1992).

Geertz (1988) raises the concern that such research "may be regarded as so much verbal seduction; rhetorical artifice designed to move intellectual goods in a competitive market" (p. 142). Not above the occasional trope himself, Geertz takes delight in language, and his accounts render human activities with enviable vividness; he also warns against the risk of aestheticism, the danger of seeing the sole value of an interpretive text in the pleasure of its reading. But, he adds,

> the risks are worth running because running them leads to a thoroughgoing revision of what it is to open (a bit) the consciousness of one group of people to (something of) the life-form of another, and in that way to (something of) their own. What it is (a task at which no one ever does more than not utterly fail) is to inscribe a present--to convey in words "what it is like" to be somewhere specific in the lifeline of the world (1988, p. 143).

CHAPTER FIVE

JACK'S STORY

> *It's hard, I mean, if I stay with a friend for a night, or borrow a few bucks --I won't drink it, but if I did, I mean, it's no one's fault, not even my fault; things happen. You know. (pause) Sometimes (pause) ah! (becoming tearful) things do happen, but they help. They help you, if it hurts a little. And you think, hey that wasn't as bad--(crying quietly) It hurts. It hurts good, though.--I've seen it get better, but I've seen it worse. It can get worse. If I drink, it could. You know, I mean, I could die, that's about as worse as it could get, I know I can't go through that recovery. I don't-- when you wake up (sigh, tearful, long pause) you're alone. And you don't want to be, but you'd rather be alone than in the cemetery.*

Jack is a 49 year old man whose conversations with me profoundly affected the development of this work. His narrative carried me into a world in which I no longer felt safe, comfortable, or content. I offer this lengthy, minimally edited narrative as a chapter in its own right, because I believe it sets the tone for the rest of this dissertation. I also offer it as an opportunity for the reader to gain a different kind of access by reading this chapter first, then reading the rest of the study, and then returning once more to re-read this chapter. This is an invitation to evaluate the quality of the study by considering how one's understanding of Jack's narrative has or has not been deepened and extended by the interpretive account laid out in the subsequent chapters.

Portions of the narrative do not appear here because they appear elsewhere in this work, and some portions touching on interactions with others I made the difficult decision to exclude in the interest of protecting Jack's confidentiality. I have also occasionally excluded portions of the text that were of minimal analytic interest or which included side comments and digressions not relevant to the story being told. Where I have edited the text, ellipses (...) appear, except for my "Mhm's" and the like, which are eliminated without notation unless they appear relevant to the interaction.

Because my interviews with Jack were so meaningful for me, I wrestled with the temptation to edit his narrative in "sympathetic" ways, such as excluding portions about his drug dealing and his imprisonment, but I realized that to deprive Jack of his past would be to deprive his present of its meaning for him and for me. I have tried to edit the narrative in a way that remains most true to Jack's own voice; I have not tried to "organize" it into a story. The careful reader may note occasional contradictions, puzzling transitions, and repetitions; I believe honest readers will note the same in my work or in their own conversation. Because I believe Jack speaks so powerfully for himself, I offer this narrative without interpolated interpretive comments or commentary. As in all verbatim quotes used in this dissertation, names and identifying elements have been changed to protect confidentiality.

I first heard about Jack from one of the ED charge nurses, who brought him up in the course of a conversation with me in which she was lamenting the staff's lack of success in intervening on behalf of Marvin, a chronic alcoholic and a frequent visitor to the ED. Tempted to characterize Marvin as an utterly hopeless case, she then recalled Jack, who taught her to remember that "there's always hope." Jack used to be a "frequent flyer" who came in over and over, overdosed or drunk or with associated traumatic injuries. Now Jack is a volunteer at the hospital who began by washing the gurneys in the ED, a job he suggested for himself, and has now moved on to other positions with greater associated responsibility. One of several volunteers I interviewed, Jack offered a story of remarkable human courage and hope.

Jack is 49 years old, with two grown children who do not live with him. He is separated from his second wife; his first wife, the mother of his children, died of cancer. I interviewed Jack twice. The first interview was characterized by such an intensity and urgency to tell his story that it at times seemed disorganized, though it, too, was powerful. Nine months later, Jack's narrative was much more organized and Jack himself appeared stronger in a way I cannot quite articulate, despite some serious health problems he had experienced in the intervening months. He had found the moral voice that so struggled to be heard in the first interview, and now, recognizing my genuine interest, he gave me the gift of sharing more of his story with me.

I met him in the hospital lobby. When I arrived, he was engaged in conversation with a pale, frail-looking young woman in a wheelchair. I waited a few minutes and then approached, saying hello and offering to wait if they wanted to finish talking in private. Jack said, "No, we're just sitting here talking about her surgery." He introduced me to the young woman, with whom he was obviously close, and confided to me, with her permission, that she was HIV positive and had bone cancer; she was being prepped to have a colostomy done. I spent about half an hour talking with the two of them before Jack and I left Faith to find a private area for our interview. Jack was tenderly solicitous and jovially cheerful by turns with Faith, who responded to him as to an old friend, laughing even when his jokes were corny, listening attentively when he spoke.

I asked Jack first about what had happened in his life since the last time we talked.

Jack: Well, nine months ago I was living with Helen, a girlfriend of mine. And we stayed together at another hotel, the Five Star--I'll give them a plug. The wino and winette paradise of 16th Street. And, uh, she's doing all right now. We stayed together and I finally got my SSI [Supplemental Security Insurance] squared away to where I'm getting my check, direct deposit, because I had been robbed and I was short for money; I didn't have enough to pay rent. And I had paid rent to my wife, but we had split up because of her problems and it was affecting my life. And I would rather be homeless than to be captive in, in a situation where I'm uncomfortable. And if I start shooting dope again, I'll be back in the bushes behind, you know, in the parks, sleepin' in the trees, or wherever, you know. And it's very hard for people to understand how I, I, uh, *determine how I should do things or live... 'Cause I've got my standards and my rules that I play by.*

Int: Well, talk about that. Your rules.

Jack: Well, to me, rehabilitation or getting over a bout of drinking is simple: Stop drinking, start to eat, and you get over the hangover in a couple of days. Well, I'll be 50 in August; I'm 49. And I've been drinkin' since I've been 8 years old. I was very young when I started using drugs, about the same age. I was poppin' pills. ...And I was injecting drugs at 12. I mean, I lived a very fast and a fearless, you-can't-tell-me-anything kind of life. And I didn't have any ethics or morals about it. I, you know, I didn't go out and kill people or anything, but, uh,

(interruption)...

Int: Anyway, you were saying you didn't have any ethics, then.

Jack: You know, I was out to get my drugs and booze; I was a kid. I didn't have a job. All I knew how to do was rip and root and I was big; I was this tall, and not as heavy, but when I was 12 I was full grown, except in the head. And that's just starting to work. Anyway, I--

Int: How's that different now?

Jack: Well, I've started using--uh, first of all, I had to get goals and direction. I didn't have that when I was a kid. You know, I didn't have parents. I grew up in an orphanage in New York and then I was adopted. And I always thought these people were going to return me if I ever got in trouble. And, you know, I was just very insecure.

Int: How old were you when you were adopted?

Jack: I was about 11... Very young, but I was very mature. I was shaving in the 6th grade. That's funny but, I mean, they wouldn't let me go to the graduation unless I whacked my peach fuzz off. And I was, I looked like a teenager at sixteen years old. When I was twelve, thirteen years old, I had a pompadour haircut and Levis down on my *hips. Had sideburns. And, you know, I smoked Camel cigarettes, drank beer, and I liked beer and whiskey boilermakers. I liked them. I liked the taste. That was even more devastating. And I could get it 'cause I looked old enough. I'd drink with the high school kids and adults! I mean, adults, to me, were 20 years old, 21. I mean, they were grown up.*

Int: Now, let's come back because you were starting to say about these rules that you now-

Jack: Okay, I made a little change in my life, you know. I've started trying to straighten up and get away from drinking, drugs, and make a little something with my life. So I just made my own kind of game plan where I don't, I don't live to get high in the morning. I don't, I don't steal. I try not to offend anyone. I try to be friendly. But I also have my code, you know, like Zorro... You know, so whatever they were telling me in school, and my adopted parents, you know, like it's against the law, do you want to go to juvie?[juvenile detention hall] And I thought, well, yeah, I'd really like to go there because, you know, I don't have any pressure. But I didn't tell them that. I felt comfortable institutionalized.

And so when I stopped and thought about it, I just made my own rules. Like I don't associate with a lot of my old friends. I associate with them like hello, and how do you do. We'll talk --casually. I can't root and run with them. I can't go to the show with them. I can't go to the bar. I can't go to the park and kick it around, smoke crack all day and go crazy. And, and with drinking too. I like to drink. I loved it. I mean, it was my life. Everything I did was associated. It still is, I-- When I'm walking down the street, I'll see some of my friends and they're standing on the corner drinking a bottle of Irish Rose. That's the hot rod drink now. Well, it was Muscadoodle Berry and Thunderbird when I was a kid, and, uh, Bali Hai, you know, and we'd sit on, at ____ Park and...

dream about our futures. (laughs). And the mountie on the horse would be trying to catch us. And, you know, it was a game.

And so I've applied it as an adult now. I, I just, I have things that I,I just won't allow myself to do. And that's getting involved with people that I knew, or I knew as associates. Like my friends here somedays after work, they'd go to the bar and have a couple of beers, play shuffle board or whatever, you know. And I, I can't--

Int: You don't do that?

Jack: I, I've gone, and I've had a beer or a couple of beers. But I don't feel comfortable because it's, uh, it's tender. It's like a, a burn on your hand. You don't put salt on it. You treat it with a lotion or antiseptic and cover it up, try not to agitate it. And my liver is probably the size of two livers because it's still, I imagine, swollen from all the--I never went a day without drinking and using. For years. The only time I wasn't using was in jail or juvenile hall or when I was in prison or in the hospital. And there, they'd give me drugs. And I would always get food. I used to walk from this hospital to that little store across the street every morning and get my pint of vodka, and drink it at that little bus stop. Chugalug a pint. And get back here just in time to get a little shower and rinse my mouth, brush my teeth and push my button for my pain shot! You know--

Int: Hmm. When you were staying in the hospital?

Jack: When I was a patient, yeah. Well, that was, that's a sick mind, conniving that, and, and, you know, but to me it was as necessary as the average person going and having a cigarette after dinner, you know, relaxing and watching TV. And as a kid it was the same thing. Between classes, I'd pop my Disoxin pills or my Tuinals, Quaaludes and I wasn't a party--. I just I liked the feeling of being high, but it wasn't an escape. What are you trying to escape from? They always asked me, what are you afraid of? Everything and nothing. But I liked the feeling. It wasn't the lifestyle because I didn't *run around with dope pushers. I didn't run around with anyone. I was a solo artist. But I had a hell of a thing about reality. I still do, you know.*

Int: What do you mean?

Jack: Well, I don't like the real life that's out there, the reality is an ass kicker. So I kind of look at it, and if it's a nice day, most people wake up and-- 'God damn, I should try to get 10 more minutes of sleep, and I got to go to work.' You know, they don't enjoy it. I get up, I put on my radio or my TV, whatever, usually my radio first. I listen to my jazz or my oldies rock and roll, and I get up, wash my face, put in my teeth, my big glass eye. No, I haven't got a glass eye yet. And I freshen up and I have a smoke, and I just listen to the news, and hear the weather. And I'm thankful that I'm healthy, alive; I don't have a hangover. I don't have the shakes. I don't have a crazy man banging on my door wanting the rent, or someone that wants their TV back that I'd stolen, or, you know-- I have a clean conscience. Not clean, clear. I'm still a dirty old man, but--. And I, you know, I don't have to hide from a girlfriend and, you know, and all that. And then my reality is I get up, then I shower, I put on my--get up, my clothes--and I say hello, and hi, good morning. And I'm friendly to people and there's some of them even smile, you know, so it is spreading.

But there are nice people in the world and it's not really so terrible. Now Clinton doesn't call me to see how I'm doin', (chuckles) and then the chief general, that surgeon, he hasn't called either yet, even though I like the guy. You know, he might have made some mistakes. So did I. So everybody's got problems. So it's not me that they're mad at if they don't answer, but I used to really think that something was wrong with me. I had a lot of hangups. And-- people today live in this-- computers and, you know, they can tell me things about the world on a screen that I'd have to study in a book for 20 years.

But I've had a very interesting and fun and heartbreaking life! But I--you've seen people, I need people now; I used to be very solo. Very much to myself. And it was hard at first, but it became, to me, more of a challenge because I said, well, I'll just try this for a day and see what happens.

And I was still in withdrawal and shaking. It was from drugs and alcohol. And I was in the hospital and I was nice to the nurse that woke me up to take my blood pressure. You know, and draw my blood. You know, these are not the kind of people that you like to meet at 5:30, 6 in the morning. So I smiled at her and she called the doctor immediately. 'What's wrong with this guy?' you know, 'He smiled!' And I was nice to the day nurse.

Int: When is this that you're talking about?

Jack: Well, when I first started trying to get away from drinking and using. It was a withdrawal, I was being treated for withdrawal, and I was having convulsions. They didn't know what was the matter with me. I'd had a seizure, grand mal, I had knocked down--I fell down some stairs. You know, and they were kind of worried about it. All the other clean-up acts I did [were] forced upon me by being in jail or, I knew it was just getting cleaned up so that I could get my health back a little so I could get out and do this some more; I didn't have any intention of quitting or changing any of my, my lifestyle. And it was hard, you know, at first. Who believes you? Because I'd burned all my bridges. I had no family. I had no friends.

(interruption)

And I, uh, I was, uh, I was afraid to make the attempt because I was afraid I'd fail.

Int: What would that have been like if you'd--

Jack: Well, I did. I did fail because I was afraid to fail. See, I didn't think about it as trying to gradually change my life. Uh, uh, adjusting to people, to situations, I'd never *lived in a square neighborhood. I'd never had ever made an honest effort to clean up, to stop using drugs, alcohol, and people, you know. I mean, I was an abuser. I abused everything I had. If I had a pack of cigarettes, I would smoke a pack of cigarettes. If I had a quart of vodka, I'd drink a quart of vodka. You know, I, and it wasn't because I wanted to just drink a quart of vodka, I had-- And it wasn't that I was out of control that way, I just* <u>*didn't like Jack.*</u> *I didn't like where I was, what was going on in my life. I never knew what I was missing. But I didn't know, I didn't know what it was like to have a relationship with anyone. I mean, I knew people but I never got close to anyone. And, uh, I was afraid of being hurt, letting my guard down.*

I don't know if you've ever been in an orphanage or a boys', well, it was a co-ed place, in New York City. But every friend I had would either get adopted or put in a home. They didn't have like now where they have foster this and, uh, group homes. You were either picked or kicked. (chuckles) That was the way I looked at it.

And a couple of times, I was taken and placed in a couple's house, and I didn't work out. I was clumsy, I was big, I had a very bad attitude, and I was a tough kid. I mean, I didn't like nagging is what I called it. And that was asking me to make my bed or something. I mean, I always made my bed. Who in the hell is going to make your bed for you in the orphanage? But they'd tell me to, and then I'd get, 'Wow, what's your problem,' you know? And--'Don't wear those Levis!' And I only wear one pair, you know, that's my trademark. And "Get a haircut.' And I don't cut my hair. I curl it, you know. I had nice curly hair and, you know, that pompadour hanging down the front; now I just have the sides. And I still don't like to cut it, you know. I like it. I didn't like to do homework. Well, hell, I didn't even go to school, I'd cut. I didn't like the teachers... Yeah, I had a problem with authority. But I wasn't a gangster as far as hittin' people and *beatin' them up. I lived in my own world; I still do. But I play by your rules a little bit more. I still got my little ways of looking at right and wrong. See, I think a lot of your 'rights' are wrong. (laughs)*

Int: My rights?

Jack: Not yours. The society's—... Not you personally, no. I mean, I look at their laws on the books and I'm talking about morals and ethics and lifestyles.

Int: But like what?

Jack: Well, like you should get a good education so you can get a good job and become a doctor or a lawyer. I, all I wanted to become was alone and leave me alone! I got a little job, I was working, I hustled in a newspaper business. I sold newspapers. (chuckles) But I made money as a kid. I had a--who do you think bought me this booze and cigarettes and my motorcycle boots and my Levis? They didn't give them to me at the orphanage. I sold newspapers, I shoveled snow.

Int: See, I didn't realize that you lived in the orphanage for that long. I thought you were adopted much earlier because I remember you talked to me about your parents a little bit the last time. Do you still have any contact with them?

Jack: Well, I pray to them every night; they've been dead for a long time. Yeah. And they're still here, in a way, I—I mean, I still remember things that they were trying to explain to me, or, at that time, I called it preaching and nagging. They were right. I hate to cop—tell you the truth, but I learned; I'm a late bloomer. But a lot of the good you see in me now is from their foundation they started. They seeded it--just like I said, it didn't take effect until I was a lot older. And it still, when I think about them, I think of some of the things my Mom and Dad would tell me about life, you know. I mean, I never had people telling me anything or no one ever called me in for dinner. They rang a bell. You came and ate or you didn't; They didn't give a damn. Don't eat, eat your spinach. I never --they didn't care what I ate.

Int: So it doesn't sound like you had the romanticized view of the orphanage that Newt Gingrich seems to have.

Jack: No, he's quite a character. I'd like to talk to him, too. And I think we'd have another— Well, I mean, he's entitled to his– insanity just like I am. And that's all it is to me. I, I'm amused by it. I mean, you're the people that elected him or got him in–

Int: Not me!

Jack: All right. And Clinton too, I mean, and this [governor]. I mean, I didn't vote for any of them, and I don't understand them. As human beings, I don't understand them. And that's what I judge people by--not the color, not whether they drink or not, or whether they affect me to where I feel like gettin' blasted because they've driven me over the edge with their naggin' and their stupidity. But I just couldn't deal with people. And when I do see people that, that are in control and either hypocrites--.

I remember I had a teacher that used to drink. And he was a real nice guy as a person. He was popular even with the girls in the classrooms, and the guys thought he was cool. But the man was a full fledged lush. And, uh, he smoked, I remember because he always had a pack of cigarettes in his shirt pocket. And I could relate to that. But when it came down to the homework and all that, and making these big assignments--it was a history class he taught me. And I didn't want to--I didn't want to--who wants to hear about Greeks in tennis shoes and Romans and conquerors, Kubla Khan. I thought it was a cake or something, a pie, or cobbler. But it was Kubla. And, and, you know, I just--it didn't relate to my life. If it didn't apply to my survival, I didn't need it, and that's where I was, I was trying to survive in New York City and I was scared to death. I'd been out on the streets. I ran away a few times. And, uh, hey, I did fine.

During the tape break, Jack begins telling me about one of the times he ran away from the orphanage, when he met a woman who took him in and looked after him for a time.

Jack: ...said here, go ahead and make yourself at home. Can I get you something to eat? And this woman met me at a bus stop. And it was raining and I guess I didn't act-- ...And she took me in, and it was raining. And I was kind of shy too, you know, I didn't talk to, what did they call them, street people. They didn't have that slang (inaudible). But I mean this was society, a lady that had an apartment and a husband, you know. A younger woman and they didn't have children yet. And I didn't want pity. So I didn't know how to accept this. She was nice. She wasn't doing it for pity or for stamps or for approval or for money. And, and, I started realizing there are good people in the world. There are nice people, whether they drink or not, they can still be nice.

But a lot of these people were using pills back then; everyone took diet pills. They'd get revved up in the morning. They'd drop three or four Dexadrine, Dexamils, amphetamines, to lose weight. And they'd be all wired up and talking trash. Then they take two or three Miltown at night, and Seconal to go to sleep. And, you know, they were chemically using and it didn't bother me. But the same people are telling me I can't get loaded because it's not good for you.

Int: Go back to this woman, though, for a minute...What happened then? You stayed with her for a few days or?

Jack: Well, she met me at this bus stop. It was raining and I lied to her. I told her I was unemployed. I just lost my job.

Int: How old were you then?

Jack: I was about ten. Just before--you know, she said, what kind of work do you do? And I said I'm a restaurant worker. Well, I was. I worked in a cafeteria at the orphanage. I was the only kid big enough to carry the garbage cans out. So I was, uh, -- that's work, you know.

Int: So you told her you were--lost your job... Which [was] true, since you ran away.

Jack: Well, I didn't lose it. I just misplaced it. (laughter) I liked it. I liked physical work because I felt like I was accomplishing something in this--you know, as a kid I had no values. I, I didn't know--I knew right from wrong but I never knew what it felt like to earn the respect of someone. I knew how to earn a buck, and I wanted to be accepted and to be liked and approved. In order to do that I could out drink my buddies, I could score more drugs. I could take more drugs. I still have a tolerance like an elephant or a water buffalo. And then I could get in more trouble than anyone else. And that made me real popular with my peers. Lot of the gals thought I was slick and funny.

Int: But now, wait, we got off the subject of the woman that--

Jack: Yeah. Well, she picked me up, not picked me up, she met me at the bus stop. She said, well, and I told her that I got kicked out of my, uh, apartment. I told her my roommate wanted the rent and I didn't have it. And I'm lying already and when I lied, I guess she picked it up that something wasn't kosher because I get red as that balloon over there. And I stutter a little. I used to stutter quite a bit when I was younger. And, and, uh, she said, 'Well, come on,' she said, 'I'll get you a towel and you can' --it was raining pretty hard--'and dry up.' And she lived about a half a block from the bus stop. I wasn't waiting for a bus. I was thinking about where I could go to camp out, hide in one of the cellars that night. And, uh, we, uh, went to her place and she took my shirt, gave me one of her husband's, what do you call them, Pendletons. And I was soaking wet. I had on sneakers and I had to take them off too. They were soaked. And it, it had the name of the school I was in, the orphanage. Stamped. (laughs)

Int: A little tip-off.

Jack: Yeah, you know, branded. Wanted dead or alive. I felt kind of like the fugitive, you know. Like that movie with David Jansen. That came out after, but I laughed the first time I saw it because that's what I was kind of doing. Just going day by day. It was *interesting. I enjoyed it. It was scary. It was also fun. You know. Even the hurt didn't hurt--weren't as bad as if I had not have been doing what I was doing.*

Int: Now, what do you mean when you say that?

Jack: Well, if I had stayed in that orphanage and became manipulated by them... I, I, uh, I just couldn't take those people hacking at me all the time. And they'd make fun of me because I was so big. And I was, I, I, I had a very bad temper. If you picked on me too much you were in trouble. So everyone knew that. They didn't pick at me but they'd make fun of me. Like I'd get real mad and, I mean, I could put my fist into the wall and break the wood or the plaster. And that's nothing to be proud of, but I thought I was hot crap, you know, I was--don't bother me, please. And I did push ups and I was, you know, lifting little weights. They had dumbbells there. Not the kids' kind, but the real McCoy. And--

Int: So someone being, uh, not kind of being molded by them was important.

Jack: Yeah; oh, I would never submit.

Int: And so when you went off on your own--

Jack: And this was not the first time--

Int: --like going to stay with this woman.

Jack: Yeah.

Int: You really felt like you were on your own and it was an accomplishment, kind of.

Jack: I was achieving the progress and I knew it was--that I hadn't told her the truth, but then again I really didn't take her on a trip, you know, a bummer. But she did ask me about the shoe and I told her the truth after that. She said, 'Oh, well, what are we going to do?' I said, 'I don't know about you, but I'm going to put that wet shoe on and start makin' tracks.' And she laughs and says, 'You can't go out.' And I said, 'Oh, yes, I can.' And I said, 'Thank you for the'--she fixed me some soup and I had--and then a hot cup of coffee, not milk. You know, I was an adult. And I was makin' it, one way or another.

She said, 'Jack, just stay here. We'll work something out.' And I thought, uh huh, you'll call them and that will work it out, and I won't be here. And I started to leave and she grabbed my arm and said, 'Come on, just sit down. Why are you shaking?' I was. I was trembling. I was scared.

'Cause I had done this many times before and they had threatened me with the juvenile detention the next time. And that's why I couldn't trust anyone. And I had to be very careful, and come up with things quick. And they didn't have shelters like they have now, and soup kitchens. I worked every day in a restaurant somewhere. Washed the dishes or something, made money. I [had] stayed at a wino's place. It was a shelter for alcoholics, soup line, you know, and then they give you a bed at night. And I'd stay in the morning and clean up. I mean, this was a week I'd been gone already, and I'd been doin' all right. Things just happened. Every day, I'd get by somehow.

And now this woman's going to let me sleep on the couch, in a house? You know. I was, come on, I didn't believe it. It wasn't a house, it was a studio with a large bed you pulled out of the wall, a Murphy bed? Well, the bed always stayed out and in that enclosure she had like a sitting room. She had her makeup, and she had this dressing room. So it was like a one-bedroom and a studio built into one. It wasn't real cramped. And she was nice. But I don't—didn't trust anyone. I didn't trust myself.

And she said I could stay and we'd work it out, like I said, and I,I knew I had to get out of town. And she knew the name 'cause she saw the shoe when I was still tying it. She said, 'Come on, just take it off.' I said, 'Well, I really, I've got to get out of here, 'cause if they get me this time, they're going to put me, lock me up. And I don't want to do that. I, I, just, I'm scared of it, and I'm scared wherever I am. But that scares me *even more than I can imagine. That's all I can tell you, lady. I don't know what it's like in that juvenile hall. I've seen them. I've seen jail. But I am not going there. If I do go, it'll be for doing something wrong, not for trying to make it on my own.'*

She said, 'Well, I won't call them.' I said, 'I don't believe you.' (laughs) And I hit the door. I didn't have to, but I ran. I mean, physically ran out, down the flight of stairs, out into ____ Street and --I remember the street number. And she yelled at me and I was about a half a block. I'm running and I don't know where I'm going, and I think about it, and I stopped. And she caught up to me. She wasn't chasing me, but when I stopped she kind of walked fast up to me. She put her hand on my shoulder and said, 'Come on, just, let's go back.' And I said, 'Okay. Let me know when you call them so I can get out of here 'cause I am not going up to juvenile hall.' She said, 'All right, I won't call them, now, but I will tell you if I'm going to call them.' I said, 'Uh huh.' And I went back.

She washed my clothes, dried them, I had dinner. I met her boyfriend, her husband. I really don't know if they were married or not. This is, like I said, in the late 50's and they didn't have people like livin' together and all that. Even though the hippies were startin', and free love and all that. It was still a couple of steps behind, you know. We hadn't hit that love generation yet. But it was the rockin' 50's and, you know, there were rebels without a cause, kind of, that's what I was beginning to feel like. James Dean. And I couldn't express myself. Now I can, you know. Uh, I can't relate to even rememberin' how I feel like that. Right now I was thinking about it-- I was really trapped. And terrified, not scared: terrified.

And I became, I thought, close to these people. I liked the guy. He smoked Pall Malls and he drank, uh, bottled beer, you know. And he gave me a beer. Said, 'Don't tell *anyone, not even my wife.' And I said, 'I'm not gonna tell her,' as if she didn't know. I mean, you know, she's in the next room. And I had a glass and he had a bottle. I mean, what's the difference?*

'Are you going to go to work, are you going to go to school?' 'Well, I'm not going to go to school.' I, I was trying to get enough money to get out of the state. I wanted to go to California and work in the, near the beach somewhere. I figured I could get a job as a lifeguard. (laughs) That's a job I could dress--I could afford that kind of a uniform, you know. The dress code fit me fine.

Anyway, I did, uh, let them convince me to stay in that little dressing room. And they made a little bed. I told them I liked sleepin' on the floor. And it wasn't a lie, 'cause in the orphanage, I would not sleep in those bunk beds because if I ever did get a bottom one, it would be some other yo-yo my size because they put me in with the older fellows, since I was big, and the thing would fall down and I would wind up with 95, 100 pound person coming through the springs, falling on me at night, where they'd shake the thing gettin' up in the top bunk. So I'd get out and sleep on the floor. I still like it. I do. I like a hard surface. And I sleep on my side and I don't roll around. And so it was nice.

I stayed with them a week. I had a job at Phil's Cafe [and] I thought I was the next thing to Jesus Christ because I was workin' for a buck and a quarter an hour, and I knew how to wash dishes (laughs), you know. And I could sweep the kitchen. I helped make the mashed potatoes. And this was, you know, just a mom and pop kind of cafe. But it was working people came in, and I was nice to the customers. And I was making 12, 13 dollars a day with my little tips.

I paid the lady for the rent and she almost started crying. And he used to give me a drink after work too. He was an alcoholic, Phil, the cook. And he was in the army for 100 years and he'd tell me about Pearl Harbor and all. You know, the war stories. And I was amazed at what he'd been through. And I'd talk and he'd pour and the more he poured, the more I'd listen, you know. And, I mean, I really liked that job. I almost dissolved, but I was—and I'd stay overtime. I got my meals, I mean, I was doin' good. And I was proud of myself.

I then decided I was going to have to get a place. And they had hotel rooms there, like the one I'm in now; I really made a lot of progress, huh? I was just thinking of that this morning. (laughs) 'Cause I was thinkin' about what we were going to talk about last night before I went to bed. And I thought, gees, I'm still in a hotel room. (laughs) But it's a difference of attitude, and, and, and feelings, and how you feel upstairs, you know, and how you're accepted by yourself, not others, by yourself. And I was always— didn't think too much of myself.

And I told them that I was going to get a hotel room down about four blocks from where they lived. And I thought I could do that and be all right. And they said, 'Jack, don't you think we should call the authorities and let them know that you're all right?' I said, 'Sure,' and that night I booked. I took my little monies and I got out of their house. I ran. I was on the road again.

I went by Phil's in the morning. He opened about 5 to get ready for the breakfast people. And I told him I had to—I was traveling. And I hitchhiked from New York to one of the suburbs and I had about 35 bucks, which is pretty good. And a little flight bag. I *really felt bad. And I didn't write notes, I just-- booked. And that was the first time I'd ever done it like that. And it continued like that for about 20 years, you know.*

I got caught eventually and went back to the orphanage, but--and they took me into juvenile hall, and then the people that adopted me saw me one day. They were -- shopping --and I guess they eyeballed me and I asked them, 'What the hell's wrong with you?' Why don't you pick one of the other kids that are younger, you know. And my Mom was only 5 foot tall. I was taller than she was. I was as tall as the man that adopted me. He was 5"7", and I was almost 6' tall! And they said, 'Well, we like you.' And I just couldn't comprehend that. With all my heart, I swear to God to this day, I still remember when they said that. And I, I just looked at them like, you know, they need professional help, you know. (chuckles) Talk about me having problems.
Int: You couldn't imagine that you were likeable.
Jack: Yeah, and for God's sake I didn't have black hair and brown eyes [like his adoptive parents]. I had red hair, big blue eyes, a real big smile and I laughed loud, you know, I was clumsy, kind of weird lookin'. Not kind of! I was! I mean, I was taller than my teacher! And I would come in the class looped. (chuckles)

And, and my abuse wasn't abuse. It was survival, and I enjoyed it; I'm not lying. I didn't have all these problems. I did have problems but, to me, I didn't consider it a problem. I liked getting high. I mean, I still do. I'd be lying to you and, uh, I, uh, I didn't know what they were talkin' about. If you understand that; it's kind of hard.

And, and the, uh, I had problems. Everyone has problems. But I didn't know what they were talking about; emotional survival is my problem. And, and trying to survive in a society where I didn't fit in.

And they adopted me--they didn't adopt me [right away]. They took me out for a test run, you know. We went to their house. They didn't have a house, it was an apartment. Two-bedroom apartment in New York City. I don't remember how I felt but I just was very uneasy and I knew it was a bunch of bullshit. I knew whatever they were thinking about, I wasn't going to have any part of it. Second of all, they had a little bit of money. They had a car and, and nice clothes. A refrigerator like I'd never seen before with food and ice cream, you know, money didn't seem to be anything to them.

(interruption)

We were interrupted again and decided to move to another room. While we are going there I recalled that the last time we had talked Jack had brought up the idea of having a place for "frequent flyers" to go. The conversation picks up again on this topic.

Int: Uh, you had brought up the idea of a place, and I remember you talked about having a place that was like the waiting room but not the waiting room?...

Jack: Well, my idea, what I was trying to express, isn't necessarily for someone who needs emergency care. Let's face it. You know what we do when we're livin' on the streets. We're surviving-- and barely doin' that. We get malnutrition. We call it, um, hypothermia. Two or three people a week are found in sleeping quarters with nothing but their clothes on their back. And maybe a please don't rain kind of cover. And they do freeze to death or they develop pneumonia and a lot of them are HIV positive. Let's face it; this city is, uh, a melting pot of people that, that are either very wealthy or very un--: unemployed, unable to get any help, other than maybe GA [General Assistance]. Sometimes they have trouble gettin' on that. And I don't know. You must really have a problem [to have trouble getting GA]. But some people can't read the test or forms, and they're too embarrassed, too shy, or too dumb mentally, they're too uh, or maybe have too many psychological, mental and physical problems to get down there in time to fill *out the forms... But, you know, and people are so ashamed. You know, if you had a job like you--. You know, some people are one pay check from being broke as far as an income. You don't believe me, but it's true.*

I've met people here that were--one of those gals I knew was not a registered nurse but a nurse's assistant. And I saw her at a shelter. And we became real good friends and she said, 'Jack, I don't know what I'm going to do.' She got kicked--her roommate and her had a fight. They not only had a fight. He beat her up. So what did she do? She called the police. They took her to an abused place for women who get beat up. She was at that. She stayed a week and then they had to let her out and they found another place. By this time she was unemployed, and she had workman's what do you call it? No, unemployment. I don't know. No, comp because she filed because she'd been beat up. And he broke her jaw. Nice guy. And she wasn't an alcoholic, wasn't a drug addict. And she wasn't a prostitute. I mean, what else is there in life? I mean, she was uh, as disabled and out in the cold as anyone I've ever known without any real bad vices. So I told her she had to get a few to play the system. And it's the truth! you smile, but you got to work the system because the system is sure in the hell going to work you.
Int: Well, talk about that.
Jack: I'm going to. I'm going to make it real simple for you.

When I was a kid I told you how I ran away from the orphanage. I had to make my own way. My own little life. It wasn't much but I didn't have to stick a gun in anyone's face. I didn't have any family. I didn't have any friends. And I didn't have any God damn experience in anything, other than emptying garbage in a restaurant, you know. Selling newspapers.

But I knew how to be nice to people. And I knew right from wrong and I knew if I didn't like anyone, I'd just stay away from them. So that kind of limited it--to me, how I was with people. I either liked you or I didn't, you know. Same thing with the system. This is what I would like to see happen--well, I don't know, and not just here, but in <u>*all*</u> *communities. It's not a drop-in center. Drop-in center is fine. That's where you can score your drugs, have a quick drink if you're shakin', meet some buddies, shoot some craps, buy some dope, and eventually get thrown in jails, you know. Becomes a melting pot...*

Our system, what they call um, social service (chuckle) is sad...Now, when I came into this world, I was unfortunately thrown in what I call the system, where I was issued a bed, or, in my case, I had a bassinet. But that was mine, temporarily. I was going to get out of that orphanage, you know. It's all about getting out of something. To play this system, you've got to be in the system.

Some people just stay on the fringes. They don't get involved to where they need a shelter. They just need social services for counseling. You know, they, their family and their life is able to hold together and heal and hopefully progress. You know what I mean? They get better. They find a job or education. They get a therapist, a doctor, something like that.

Here they've got social services. They're good for two things. Bus tokens and taxi vouchers, or they refer you-- to someone or something else, a shelter, go see this doctor, and go follow the yellow line until you run out of leather on your shoes-- ...So, you're in this system and you're pulled, pushed, torn, shoved, but you're not treated like a human being. And you can only do that to someone so long. Most people crumble and they don't come back. Screw it, I don't stay in shelters. I'd rather sleep in a doorway. I don't eat at St. ____'s [food mission for the poor], there's nothing but bums there and *they all got lice. You know? And they're all crazy. I'm gonna tell you something, some people in Joe's Diner and, uh, McDonalds, Jack-in-the-Box--they have lice too. And they've been out in the street all night too...*

But basically you're still that person, only you don't have someone tellin' you what to do. And you don't have all these rules. But you've got rules right on the wall at McDonald's or Jack-in-the-Box where you're inside drinkin' a hot 10 cents cup of coffee, my butt! It's 60 cents for hot water with coloring in it. And then there's no loitering. You got to be a pest or a customer and try to use what's left at the restroom. Because you know, as soon as people get in there, all the toilet paper is gone. Maybe the sink too, if they can sell it. But there's no paper towels. And, and, so your place to wash up, clean, maybe dry shave is gone.

Before it got as bad as it is now, that's what we would do. We would find a base of operations. (chuckles) Now I didn't run with the clique. I was always a loner pretty much. I had buddies and a couple of gal friends. But we had a common ground: our alley, we used to call it. My doorway. My panhandling spot. My customers. I used to call them my connects, my clients. I wasn't a hobo; I wasn't a bum; I wasn't a derelict; I wasn't a drunk; and I'm not an addict! I was a therapist, and I was giving this square something to do, and I was helping them to feel good about donating to my little funds so I could get something to eat or drink or get high on. And I was; I was a social worker myself. I was very social to these people. I told them a joke: Hi, how ya doin' today? Pardon me, sir, I'm in dire need. Would you help me cure my hangover? I need 50 cents and I, I really it's not for food, and it's not for shelter, I need a drink. And men would give it to me. And I'd also get old ladies with a bunch of those Awake magazines and go to heaven in three easy steps, you know. (laughs) And then I'd get the 12 steps, you know, go to AA. You don't need a drink. I said, I do need a drink so I can go to AA. I'm not *drowning. And, you know, it's a system. And you have to use the system their way or you can't play ball with them.*

Int: Now talk some more about that.

Jack: Okay. They want you to listen to them, follow the blue line to go to that office, tell the lady this. Of course, there's five, six hundred people a day goin' through all these outside places being referred to go to the hospital. Let's just use--you want just the hospital, as an example? ...I'm trying to tell you it's not just --it's their social system of the city of _____ and the State of _____, as I know it. And I know it well. You know, I do. I feel like I am qualified to a degree and, in fact, I'm probably more qualified than some of these social workers who are just social disasters, is what they are. And they're not sincere in anything that they're doin' other than picking up their paycheck up; they don't have common sense, so how can they help someone who is emotionally and physically at bay with life?

You go in and ask them for a bus token. They glare at you like you fell out of some gosh darn tree and hit your head too hard on the concrete. You've got a sling on your arm and a glow in your eye and that's 'cause you need a drink. And you're sick 'cause you haven't been eatin' and you're shakin' and they ask you what's wrong. And you tell them 'Nothing, I always walk around in my arm in a sling, with my eyes crossed, and I'm mad inside and I'm angry at you, and you're askin' me what I need? Three hots, a Cadillac and a condominium, just for the night.' They tell you to go to a shelter. Okay, where is it? Well, you go down to 4th and Washington and it's called _________...They're going to put you down on the floor with 20 and 30 other people all around you. And now it's two or three hundred. It's like a big cage...

If you stay at the shelter, you do get to clean your clothes or maybe shower. You still don't have deodorant. You don't have a toothbrush. They don't give you toothpaste. And you don't get a haircut. And if you have lice, they do give you something to wash and kill them. But let's face it, you're--. Just to get to that point in life, you've got to work the system. You've got to play games with people.

You've got to know where I could go to get a hotel for a week. You know where you could go to get a hotel--let's say, right now, you just--I took <u>*you*</u> *right now, leave your purse here and your tape machine. Just what God gave you right now. And you've got to leave your 20 bucks from your pockets so you could call home, huh, collect. 'Cause, you know, they won't accept collect calls and home is 200 miles away. Now just think about it. Where would you go?*

Int: I don't know.

Jack: Okay, I'll tell you.

Int: Well, I'd probably go downstairs to the [hospital] lobby.

Jack: What for? You like watchin' Days of Our Life? The Young and the Useless? The Edge of Wetness? That's a good soup opera. Huh? What are you gonna do? I'm askin' <u>*you*</u>*. Now, Ruth, you just, uh, lost your job and you don't know anyone. And you lost your job in [nearby town], and you had 20 bucks and you took a bus up to [city] because you heard you could eat up here and maybe stay in a shelter. This is good 'cause they didn't use to have even this when I was growing up. But even as an adult, they didn't have shelters like they do now.*

Okay, you go to St. ____'s, you stand in line for 3 hours because you didn't know how to cut the line. You didn't know that the women and disabled could go in early, and even the go in early line is like the old regular line. And the old regular line is 3 blocks *long, and these people are sick. They've got TB and diarrhea, which is nothing to be standing in front of someone who's defecated in their pants, or urine, and the odor is prevalent. And they're coughin,' and you see lice on the guy's coat in front of you, or the gal's. You know, not all of them. But there are more than there should be. And, with my luck, you're standin' with me and all right, they'll be in front of me (laughs), or behind me and I'll have a lunatic behind me listen' to rap music, snappin' his fingers and chewing a wad of some kind of thing, gum. Smokin' crack around the corner, and they're goin' crazy. This guy drinkin' wine. And you're trapped in this line for about an hour, two hours. Now that's* <u>average</u> *because some days, the food's so bad even the bums don't come. And the line is so bad that they just say, screw it, we'll go to the other place- ______. Or we'll got to ______, or there's places in ______. But you don't know about these other places, like I said.*

All right, you're workin' the system and you come up to me and you just told me you're from [town]. Well, have you ever stayed in—what shelters? You don't know where it is. Well, uh, and you're Ruth and you just got here. Well, I'll tell you what: You could go make out uh, a list here and I'll tell you where to go. We'll have our lunch here. By the time we get out of here, it'll be 2:30 so we're going to really have to hustle to get you a place for tonight. You can get into the lotto, it's a drawing. You might get a place at [shelter], and you can sleep on the floor there and know that you shower, and they give you a—maybe, if they don't Bogart it and snatch it out of your hands—they'll give you a sandwich and a carton of milk at night for dinner.

Or you, being a woman, you can go to the women's shelter down on Franklin Street. But that's a drawing, too. They'll take 20 people. And there's like 300 people *applying. Don't uh, uh me. And this is, we could do this today. I'd like to do it with someone with a video camera.*

Okay, but we'll go to two of these places because they're only half way across town apart. This way you've got two chances, better than none. And if that doesn't work, we can always go to ______ House which is the crack kingdom of the [skid row area], and the Episcopal sanctuary, where you can get in there. And being a woman, your chances are a lot better than me because I have to get something physically wrong with me to get a referral to get in there. But, of course, you just became pregnant, because if you tell 'em you're pregnant, your chances of getting in are better. And tell them you have TB and you will get in. Huh? And if you do get arrested, tell the vice officer or the cop that arrests you that you're positive for TB and you're 4 months pregnant. This way, they can't x-ray you and book you in jail. They have to take you to City Hospital, and they usually kick you out of the lobby there. So you do that.

We couldn't get you a place at any of these other places, and you're out on the street... But you're hangin' around with me, and I've been around the streets, and I get popped because I had warrants for jaywalking, panhandling or probably just because the cop didn't like the way I was lookin', and I'd been drinkin' and they knew me, and he stops me. Hey, Jack, what's happen,' brother? Nothing. There it is. And I give him my ID and he writes me a citation for open container. This makes number 99. (laughs) Failure to appear all over my—thing. 'Here's one more, Jack. Clean 'em up.' So I get for drinking in the doorway, open container of beer. 'And, young lady, what are you doin' down here, huh? Don't you have anymore sense than this? Okay, well, all right, you guys better find some place to go or you catch you out here in these doorways again, you're goin' to jail!'

All right, let's go to the hospital. It's drizzling out. It's colder than a well digger's ass out here. And, man, I could sure watch the--what's that program? General, or Night Train, or, no, General Hospital, or Emergency is on TV. I watched that the other night. I almost felt--double duty, you know? (chuckles) Then we go into the emergency room waiting room, and just sit down.

And right now, Bosco, the security guard says, 'All right, what are you doin' here Jack? You don't have a yellow thing on your hand. Are you waitin' to be seen?' 'Oh, I forgot already, Mister, I was so sick that I had to rest so I could go stand in line.'

And I'm tryin' to figure out what's wrong with me. You've got a--let's see, you've hurt your back. Let's just use that one. And I, uh, got pain right here in my lung. I don't know, I keep coughin'. I probably have a good cough, you know, being outside for the last month. Sign up, go to this window and they'll register you.

And I want you to feel quite at home here. At least you're warm. There's a drinking fountain. A restroom where you can even wash your hands if they haven't broken it or flooded it out. And, uh, of course, you're sittin' in there with people who, unfortunately, have a job, pay taxes and think that they are entitled to be helped before you. They're sicker than you are--whether they are or not they are the sickest person in that waiting room. But so are you. You know what I'm sayin' now?

Int: Yes.

Jack: Yeah, and now you go--finally you're registered, branded with the yellow thing on your hand. And you've got a sneakin' suspicion they're not telling you the truth, to go sit in the waiting room and we'll call you. Ha,ha. 'Cause you just don't see anybody getting *called; if you are called anything, it's a name you're not supposed to use! And you take your lovely chair there and there's a couple of people sitting around you that don't look too friendly. One guy's talkin' to the water fountain. And you find a little space where you're isolated and you're comfortable and you figure— I'll do my own time.*

You sit there and you wait approximately an hour and a half, two hours, and you hear names over a muffled speaker but you can't figure out what the nurse is saying. Come to the triage. What's a triage? I'm looking for the tree and I don't see any garages and, uh, you know, uh, it's very confusing, and you're not feelin' good. Let's say you really <u>*are*</u> *hurtin' and you really* <u>*are*</u> *sick. Most of the people are—at least in their mind, they're sick. And they're uncomfortable, to say the least.*

You get to the nurse's thing about 8 hours later. Now, by this time, you've snuck outside, bummed a cigarette, drank a little water, used the restroom. Now you're a little agitated because you've been bumped around, messed with, by the nurses that have taken your blood pressure and your temperature and your respiration... You already felt this hostility towards you, a dislike, a glare, sarcastic words, kick in the ass. Plus, plus you're <u>*not*</u> *really feelin' good, and now, you're feelin' worse.*

Finally, they call your name and you go into...this ward, and there's about nine gurneys with an array of dis-assembled people, with various parts of their bodies hanging over the side. And 90 percent of them got an IV in 'em, and they're sticking their arm out and you see them propped up. Some with their eyes open, some closed. A few people strapped down.

And a desk with a bunch of doctors that you don't know what they are because they all dress pretty much the same. And they're all joking, drinking diet Pepsis, eatin' health foods, oranges and bananas. Ha ha and la la gagging. 'And did you see Joe, he was out there again! Ha, ha, son of a bitch is crazy! You know he's gonna die if he doesn't change his way.' 'Yeah, well, that'll be one less nut we have to take care of today.'

Of course, you don't know--this is your first time here--that there's a triage, that if you do get shot or hurt seriously, you know, critical, they rush you in there. And you don't know there's the obs[ervation] ward across the other hall, and then there's the west side, and it's the same thing, depending on your situation. And they've got three of these things goin' and all these doctors aren't doctors. There's one doctor that's an MD qualified to administer a triplicate prescription medication for pain, a shot of morphine, or a heart medicine, critical medicine. The rest of them are residents, interns, or medical students.

And you're sitting there wondering what this guy is trying to do to you. And he's saying, 'Well, uh, does this hurt?' And he taps your leg and you kick him in the--and, uh, 'Let me see your eyes,' and you tell him, 'Doctor, it's my back, you know, I fell down on the bus and I really hurt myself.' 'Yes, now, follow my finger,' (chuckles), you know?

Then you have, uh, a doctor who's doing this and the nurse says, 'Doctor, uh, do you want a UA and a blood and, uh,' 'yes, and, uh--'. So there he goes and sits over there near his desk and he's writing some more. The nurse comes in and draws blood. You give him a urine and you're wondering when he's going to look at your back.

Then he comes back with a rubber glove and wanting to do a rectal exam, you know, that's getting closer to the back. But for the life of me, you can't figure out what they want to look in your rear end, because you've got either tonsillitis or glass in your eye. But they have to give you a rectal exam; it's part of the exam?... But I really kind of wonder what this has got to do--so you ask them and he says, 'Well, I'm a medical student (chortles), and we have to do this as part of the examination so that we know how to treat you or what to treat you for.' 'Okay, doctor, thank you.'

And then this goes on, and they're checking for blood. And then you start worrying, wow, maybe I got more wrong with my back than I thought. And then another nurse comes in and they hang up an IV because you're dehydrated and you had low-grade fever. And then another couple of doctors come in there with the doctor telling them, 'And this patient, er, er, er.' And they're making the rounds because they're changing shifts. See, now you're waiting in the room, now. You've been in there for an hour already. And you're not dressed. It's cold back there. You're hungry. You've got to go to the restroom. You're tired, exhausted and emotionally drained. You are drained. There is no more. Just nothing's <u>right!</u>

Finally another resident comes in with this other doctor and maybe the nurse, who's really drivin' the ship. I mean, she's the captain. She knows where the gloves are. She knows where the other instruments and the things are located that these doctors--'cause this is his first day here from [the university] where he's been going and doing his issue up at their hospital.

Finally they decide you need an x-ray. Now this is a travel just like Moses made in that desert. You know what I mean? This is not a funny picture. This is as serious *the, you know, the ten commandments because you don't know what's going on. They want a lateral, dilateral, and a chest x-ray, and a lower lumbar, and rush lumbar, and the-- you know. And you're thinking now, this is 2 hours now. You wait 20 minutes to 45 minutes; some Filipino kid about 9 inches shorter than Mickey Rooney comes in to push your big butt on a gurney through all these people, down the hall, sticks it in this hallway and says, 'I will be right with you.' And they go into this office and that's the last you see this person. You don't know where you are and no one's speaking English. You hear, 'Don't move, hold it,' click, click, and bells ringing. And everyone down the hall is layin' on gurneys with a lost look in their eye.*

And they finally get to you, put you in a room with a little technician who doesn't ask you how you're feeling or anything. You don't know what to ask them, either because they look like they're in more pain than you are. And they tell you to stand right here. And you tell them I can't get up very well. I'm not dressed, either, by the way, I only got the front of my gown. 'Just stand there and put your chin here, hold your breath, don't move,' click! 'Oh, okay. Just sit there. We'll see how it is.' And they check it and they come back in about 10 minutes; that's good. 'Okay, now we're going to do your back.' They get you on the table, a cold table, and you're embarrassed because, you know, you're doin' the half dance with half clothes. They get your picture of your back. And now he tells you, 'We'll put you out here and they'll take you right back to where you were.' And they do, but it's another 45 minutes, maybe 30 minutes.

Now you've been here almost 9 to 10 hours already. You still haven't seen the doctor. You don't know this, though. They've got these pictures along with all these other pictures. And you look in this room and there's about 10 people sitting around talking together. And then there's two guys in this room with a big screen, black things up there.

And they're looking at pictures of x-rays. Hmm mmm, hmm mmm, look at that one, hmm mmm, hmm mmm. And then they finally come and get you. You don't see your x-rays. You don't know if they've got yours or the other guy's.

Somehow you wind up back at that doctor's place. Maybe not the same place you were laying before, but you're in that ward. And you're looking at these doctors and they're still sitting there drinking coke and eatin' bananas with the nurses, talking about spring break, or how was your valentine's day. 'I went skiing at Heavenly and, you know, we only lost three people. They still have the helicopter lookin' for Troy, and ah--'.'

And finally the doctor says, 'Your x-rays are negative.' And you don't know what that is, I mean, your chest one, or your back. 'And you do have a slight pneumonia but we'll give you some antibiotics and we want you to make an appointment to go to the clinic and see a--see your doctor.' <u>*Your*</u> *doctor. Now it's about--now, I'll give you a break--it's about 1 in the morning, 12 midnight. You don't know what's goin' on now. You've got a slight fever but not enough to keep you in the hospital. You don't feel good either, and now you're worried because you don't have any place to go. And, in reality, you're sicker now than when you got here. But they're going to give you some antibiotics. Some other medication for the fever, Tylenol or what is that other one? Ibuprofen, that if you take it on an empty stomach, you think you've got food poisoning or an ulcer.*

You get ready and you get dressed. Sometimes they'll ask you, would you like a sandwich? Now you look at them and you've asked them for ice water for the last 2 hours. You just wanted a drink of water 'cause you're thirsty. They ask you because they can kind of tell that you didn't have too good an attitude. They don't like you. They're not going to ask you if you want anything.

But if you have any rapport with the nurses taking care of you, they might be kind enough to, to ask you if you'd like something to eat. And, of course, you don't believe it. And by the time you answer, she may be gone. But if she's still there, you get a cold sandwich and orange or apple, banana and a little container of low-fat milk, because they don't want you to have any blood, heart trouble. 'Course your pressure's way up there now too. And that's your sustenance for the evening, and probably till noon the next day when the soup lines open up...

You're looking around you, trying to figure out what's wrong with all these other people. They're lookin' just like you. And they're in chairs and some are taking the place that you had. Some are just getting undressed, and they're moaning in Spanish 'cause they don't speak English and the nurse doesn't speak Spanish, that they're sick and so they have to undress this person. And you can see that this nurse is angry 'cause this patient stinks.

So you did get your sandwich though, but she doesn't tell you that after you're dressed you're supposed to go up there and get that piece of paper and take it to the nurse's desk and she's going to get you the medication because the Pharmacy is closed. And she's going to make an appointment for you to come back and go completely crazy the next day, or maybe a week, you know, depending how it works that night, 'cause it changes from clerk to clerk. Whatever they feel like doing, they do that shift. If they're not in a human frame of mind, you're in trouble.

So you go to the triage desk and Cindy will give you a smile and tell you you're okay, Jack. Come back here, go to this place, and they give you the medication and you've got an appointment for hmmmmmm, let's see, today is the 16th, on the 19th at

9:00 a.m. You go to 1M3 and come early 'cause some -- you have to register. Just like, you know, you're some kind of sex offender or something. And you tell them you'll be there with bells on.

You walk out back out through the lobby and you don't know where to go. You forgot that you don't have any money. Of course, that was nothing new, so why should it make any difference. But you're at [the hospital] and in order to get downtown, you'll either have to walk all the way with that bad back and no coat. It's raining or cold out. Or maybe you can sit in the lobby 'til the sun comes up. And then maybe you can figure something out within this time.

Well, you do. You figure out that if you sit here, you'll wind up in the psych ward before--you will, you know. Or you'll go out and have a cigarette and maybe you'll start talking to someone. And so then you meet me out there. I'm a different person, you've never met me, and I'm sharing one of my last cigarettes that I smoked half of, butted it, because, you know, at $1.39 a pack for generic generics. It's not tobacco, it's dust from the tobacco that they make the ones that cost $2.60 a pack. And, of course, my emphysema is so bad that I don't mind sharin' it with you anyway, you know, and I'm gasping for air trying to tell you not to worry. It's always like this. And I'll show you where we can sit and wait till the sun comes up. But we have to be cool...

It's 7 in the morning, you go back out to the emergency room. Maybe the janitor is cleaning the bathroom. But more than likely there's someone in there doing drugs, more than likely. So you freshen up. Usually by this time, you don't care anymore; that's what hurts. And that's the truth. 'Cause your pride and your cleanliness is next to godliness and there ain't no more God. (chuckles) You've given up. It's starting; you've got it. It's like cancer.

So you just go back to the lobby, and I told you right now you can get a bus token. Should have done it earlier, but now the social workers are going to be here at 8:00. And, uh, if we're lucky, we'll get one. If you're lucky, you've still got that band on. 'Cause if you have that yellow band they more than likely won't kick you out. If you sit in the regular waiting room, at 5:00 they kick everybody out, whether you're a patient, if you're bleeding, if you can't walk. You have to get out of there.

Int: The emergency waiting room?

Jack: Yes, ma'am. Everyone is out of there. I don't care who it is, if it's raining or snowing and you're outside, and if you're not helpin' them clean up when they're done, you're not going to come back in unless you have a [yellow] band, and unless you're so sick that, uh, you know, you can't move. You can just start--you know, you refuse, and then they'll escort you outside. I've watched stick therapy.

Int: Stick therapy?

Jack: That's with that night stick, that baton? And they escort people outside and if you're a little inebriated, and if you've been—but this is your first day, it wouldn't happen to you --. But you see it happen to some black guy who's been pushed around all day, for many, many days, weeks or maybe months; for some people, it's years. But eventually something snaps upstairs and, Ruth, I'm not lying. It's no, no funny thing to see; it's so sick and sad and pathetic. But you don't notice it as much. 'Cause it's never happened to you. But now it's becoming kind of weird, it's important. And you see 'em, 'Come on, get up!' God, darn. Of course, there's two of these guys that are 6-foot tall... And they escort you outside onto a bench that pigeons have been laying on for a couple of hours. And they tell you, 'And don't come back in there or we're going to put you in the cage.' And there's a cage there, and they do put you in, especially if you resist or slap back at them because they're poking you with the stick. And if you've been drinking vodka and wine and popping pills or whatever else, you're subject to get agitated. Of *course, a lot of people are so far gone by then, they don't care about themself anymore. They just shine it on.*

And that's your first half a night and day, day and night, in [city].

Now, you can get a bus token from the social worker or the nurse. Sometimes the nurse gives it to you if the social worker is not there. You are in trouble. But you're going to start doing the same thing, you're going to get something to eat, and you go back to St. _____'s but before we go there, I'm going to sign up for the lottery at the shelter. Maybe I'll get lucky tonight. Maybe. Hm?

Now, can you imagine doing this when you're going through drug, alcohol, or physical pain, withdrawals, a broken arm, a sprained leg, fractured jaw, pneumonia?...But you've only been out for a day and half. You haven't slept. Maybe dozed in a chair. You're beat. You sign up at ______ or any of the other shelters. But you try to get as many of them as you can. But you've got to figure out how the system works. Which one goes first? So you go there, if you don't get in, you run to the other one. Maybe you get in. But usually they're so far apart, unless you've got any transportation, the only way you're going to get to any--you're going to only make two of these things.

Let me think. No, 'Maybe if I go to detox, they'll keep me.' Detox hasn't had a bed open to anyone walking off the street that I know of personally for the last year, two years. Those beds are reserved...and it is a sinful, torturous, saddest, most fearful, and disgusting place a human being can ever allow themselves to be, or treated like that. It's degrading. It's humiliating. It's infuriating. And for someone with any brains left or any *emotion or feelings, it's terrifying. (laughs bitterly) You know, it's just God damn terrifying. You see people screaming and hollering. Having withdrawals. Some of them have a wet brain which, to them, it's just home sweet home. They've urinated, defecated on themselves, they puke. They're having shakes. They can't hold water. They're vomiting right on your part of a mat on the floor. There's no beds. There's no covers, maybe a blanket. If you got any brains, God gave a, a, a sea gull, and even a rat's brain, will tell you not to put that thing on you 'cause it's full of lice.*

Int: The blanket.

Jack: It's got holes in it, blood on it, vomit on it. They wash it but they don't disinfect it. And the mats, they scrub 'em with--they have a mop they swish it with. But they forget to change the disinfectant in the bucket, so it just makes streaks on it. It spreads it from just that spot so it's evenly distributed on the top and maybe the bottom.

So that's detox. But it's inside and they do have soup once a day. Maybe a sandwich about the first 10 biggest, baddest, meanest, hardest-hitting people, they get the sandwich. And the rest of you watching, you can--they don't take one sandwich, they pig it; they grab a handful and grab two soups, a cup like that, like your coffee cup. And 'Screw you, Jack.' The strong survive. The mediocre might survive and the weak starve and they get sicker and angrier and madder and madder. And you're one of those.

This is your second day. You didn't get in the shelters so you went to the [detox center] for withdrawal. And incidentally, you need it because along the way, your buddies are all giving [you]these shots of wine to keep warm at night. Giving you a shot to wake up in the morning so you have enough courage to walk into one of these places, without wanting to take a gun, literally, and blow your brains out, or jump off the bridge... But this is the way the ball game is.

And you're in this place, getting detoxed. The guys in there are drinking, they're popping Quaaludes, Clonopins, Valiums, Phenobarbital, Dilantin, they'd take birth control pills if they thought they could get any relief from society and reality. They'd take Elavil, Mellaril, Thorazine, anything-- psychotropics, just to knock their brains out so they can sleep without someone stepping on them, yelling at them, spitting on them, MF you, you--hmm. You know, the language is so colorful, it's like being in Disneyland. It's just another world. It's just like stepping from this room into that room. Terrible.

Even for me, to this day, when I go there to volunteer--which I do. I go there. I puke when I get there. I can't help it. I am a human being. And I can't stand the smell or the sweat. Some of these people don't bathe! If they had it, they didn't bathe. They're sick. They're not crazy. They're not mean. They're <u>*sick*</u>*! Not sick that they need to be in City Hospital or State Hospital. They are deranged, they're lost, they've got no guidance. God damn, there's no one guiding 'em, other than some fellow wino who knows the system.*

Now I kind of take you under my wings. We get through this detox. And, man, you're so detoxed that you're sicker now than you have been in your whole damn life. You not only need a drink, you're going to get one whether you want it or not. You're going to get one.

Now, what do you think you're going to do? Let's say you're not going to prostitute. Who wants a hooker with a winette clothes, a feather in your hat, and grubby pants--? So what's the next thing? Boosting. Shoplifting. Or sneak and peek. You know what that is?

Int: Huh-uh [negative].

Jack: Okay, you're sitting down at the bus stop waiting for a bus. You got a bag like that. Now hopefully you haven't gotten kicked in the shins and broken your legs because I'm *going to bump into this lady. You're going to grab her handbag. You run this way. When I bump into her, she'll be thrown off guard, and you'd better meet me at 3rd and Main. And hopefully there's a wallet and credit cards, you know, but we got her ID. Now, that's kind of a bold move, but it's a real simple one and if you're good at it, they don't even connect you together.*

Or you can panhandle, for about 4 hours. If you're lucky you'll make 4 or 5 bucks. Maybe 20. They'll only tell you about the 20. They won't tell you about the day I sat in the God damn rain for almost 12 hours, shaking from alcohol and drug withdrawal, with 102 temperature 'cause I had hepatitis. But I couldn't come to this hospital because I'd been here twice last week already, and I [would] never go back to the clinic in the morning because by the morning I'm so crazy from being there all night, that I've got to go somewhere and get a drink. I've got to get something to eat. I've got to take a crap. Now where is there a restroom with toilet paper? Huh? Where would you go? The bushes, an alley. That's number two, one and two.

The next place I found is the county jail. Just go in the police station, huh! Think I'm kidding. And just go right in. I mean, I don't have a gun. I don't even have money to buy bubble gun so I'm not going to set the machine off. I go in there, I wash my face. I have a disposable razor. I dry shave, trim my beard. I brush my teeth with my finger. Huh? Wash my hair, dry it with paper towel. I got lint all over me. Hopefully, brains enough to wash your socks out. Now this takes guts, and with that borax soup and that liquid soap. And you rinse it real good. Wring them out as best you can. Put them on wet. Body heat dries them cool. Shoes like mine, shoes of society--this is--that's my heel. [shows me his shoe; the sole is coming off] I can't afford to spend 80 bucks for a pair of shoes this month. I've got a pair--I'm looking down for some.

But I had to pay--and I'm doing all right now. I'm still having problems. Simple things that most people don't think about. But these cost 80 bucks because if I don't get the right shoes, I wouldn't be able to walk, period. I have pins in both my ankles. I've got a plastic kneecap, and Schneider or schnooker pin in my hip. Now my back is curved wrong because they were supposed to give me physical therapy. But I can't afford it. Medicaid won't cover it. And to get it here, it's a 6-month waiting list. I've been on it 3 months now, 3 more months they might be able to help me with my walking. Am I mad? Am I hurt? (pause)

I live on $600 a month SSI. I am a fortunate man. I've been blessed by Jesus Christ, Moses, and uh, Nat King Cole all at once. My rent is $280 a month. That's for a room. Now for the sheets, I think I paid--I bought them at Thrift City. A blanket, pillow cases, soap, wash cloth. My towel cost me $5 because I, you know, I need a big one. I'm a water buffalo. And I should get two, because, you know. Thirty days between laundry is a long time. Hm? I better get a pair of shower thongs because John uh, has gangrene on his leg and he's in that shower. Of course, Freddie's got sores from that thing on his foot. And Billy, he's got something wrong with his stomach, and he shits in the shower. He can't hold his bowels and his urine. And everyone--there's 35 to 40 people on this floor using one shower and two toilets. A men's and a women's. Of course, you take the signs off and make a joke about it and switch them. So the old drunk wanders in and the new girl doesn't know that he's just Willy the wino and she's crazy.

Of course, you've only been doing this less than a week. Willy the wino is 6 foot 7. He was in Vietnam and his brain has just become nothing but a fog of violence, anger, waiting, pushed, shoved, 'Follow the blue line', 'What are you doing back here? God, you were just here last week. Didn't you go to the clinic?' And you find out that the guy's *not only sick, he's got diabetes and that's why he's been acting crazy. His blood sugar is all screwed up. But he never goes to clinic, the dumb son of a gun. Come on, you know what I'm talkin' about. I can see in your eyes, you're relating to this. And you haven't been doing half the problems, because I'm ducking the police. I'm ducking society. I sure don't want no one to see me that I know. That'll end pretty quick, 'cause pretty soon the reality is going to hit you in the ass, that you're doomed no matter what you do. But you'd better keep trying because if you don't, you become a* <u>*product of society.*</u>

And that's what I mean by my rules and my guidelines, my life on the streets, or anywhere; wherever I go, I play my ball game. I play by your rules, but I play my way. But I set mine higher than yours. Maybe you don't think so. But I think my rights and wrongs... they're probably stricter than yours. And my ethics are 90 percent stronger than yours. Ninety percent stronger than some of these people working here with collars and white ties, wearing panty hose and stretch socks. I got beautiful shoes, and a hole in one sock I noticed today. But I wash them every night. And hang them on my little thing. And I have more than one pair of socks but I splurged this month and I bought one of these (gestures to his sweatshirt) because the one that I'd been wearing, I wear at night now 'cause there's no heat in my hotel.

Int: There's no heat?

Jack: No, ma'am, and no hot water.

Int: You pay $200 a month?

Jack: $280. That's half my money.

Int: $280 you pay and there's no heat.

Jack: No heat. And I fixed my window so it closes now. But with all the rain, I figured, damn it, I should treat myself to—and guess how much I paid for this? (sweatshirt) Take a guess.

Int: Hmmm. $20? $25?

Jack: I paid $10 for it. And that was hunting for one, to find my size--

Int: That's a pretty good deal.

Jack: Sure is. But if you would have bought it, you would have paid $25, $20, and it would have been stolen. And the person you bought it from would have asked $25 like you said, and you might have paid it. But if you get any street smarts, you get down and you buff and you dicker. Never be satisfied. Never be satisfied, on the streets, or even in your world that they call society, I never could be satisfied; I'm grateful. I'm just satisfied when I wake up that I can breathe. That's my thank you to God. And most of these people don't think of God anymore. They give it up!. And that animal takes over in you, and anger. And that's how come I'm different. I am. But I'm no better. I was just-- God blessed me. He gave me something that you can't take away from me, and I'm tough 'cause I won't let you discourage me. You can do what you want, say what you want, humiliate me, and that's how most people get to 'em. They treat them like a piece of shit, literally.

And they don't mean it! You've been working a 12 hour shift, and you've helped a wino, a winette, junkie, a guy that got shot, 14 years old, and gets pissed at you 'cause you put an IV in him trying to save his life. Huh? Your boss is a bitch 'cause she's been working about 12 hours, but she's been on six coffee breaks, trying to make her vacation schedule fit her needs, while you're going to wind up working doubles. You know. So you <u>should</u> have an attitude. You know, it's really not your fault. You're just a registered nurse making more money in one day than I spend in a whole month, and, and, and that's a fact. That is a fact.

And people ask me, Jack, how did, how did you do it? God damn. I didn't do it. (chuckles) I didn't. I never could. I never will be the one that did it, you know. God is the one that gave me a little bit of guts to say no. Not to drugs or alcohol but to giving up. If you people help me--not all of them are bad, believe me...

I surprised you today [in dressing for this interview]. And you got a striped shirt like it's a come out of the jail shirt. But, you know, Jack, you got class. You're going to wear sweat pants anyway, and you've got that sweater, and you can make it look good, 'cause you hand washed all this stuff a week ago by yourself, and you ironed it under your bed. I got a piece of cardboard and I fold it and then I stick 240 pounds bear meat on it, and by the morning it's even got creases in the right place.

But most people won't spend that money for rent. They want to get high. They're going to get drunk. And I don't blame them because they hate this reality; ain't worth a shit. Stop drinking? For God damn <u>*what*</u>*? Huh? And that's just drinking. I'd rather smoke a hit of crack, get a rush, and, man, I'm not here anymore. Please take me, dear God, let me OD. I swear to God, I've seen 'em say it. It hurts me.*

I have a friend right now. Every time, she fixes in my room. Even 2 weeks ago, she fixed in my room. I said, 'Come on, Becky, get the fuck out of here with that shit. You know I don't like it!' 'What are you? Some kind of self-righteous bastard?' Then I catch myself. 'No.' I'm not anything. What am I? Self-righteous? No, it's that I still want it just as bad as I did the day I stopped, and the longer I'm clean and sober, the worse it is, in reality.

'Cause I do listen at people like Newt Gingrich talkin' about the very thing that I started in, instead of giving you a farewell and letting you have welfare, they're going to

start putting kids in orphanages again, and I got so irate, I threw a coffee cup against my wall. (laughs) Damn. And I had tears (pause)--and these are politicians ?--but, anyway, so-- I don't drink and I don't shoot dope. What do I do? What do I do to keep my sanity?

Jack talks about a conversation he had with himself earlier when he was despairing and not sure what to do; examining his options, he realized he could choose to deal drugs:

I can get back in the crack business. I can deal heroin like a son of a bitch. I can have a Cadillac by Friday, and that's tomorrow. I can do it. I have connections that I can go to right up this--35th Street. It's up a little bit. And the guy will front me 'cause he likes me and he's a gangster. This man is. Well, I better not say. He's Italian descent. He has body guards, Mafia, connections. And he likes me better than his own son. The man told me, he said, 'You've got more balls than the whole family that I have.' He said, 'I'd trust you with my life, Jack.' And I was flattered and I thought, boy, that's a nice compliment. And then I started thinking. You know what this guy's--I know that he's offed people. And he started in New Jersey and moved to Chicago. He's older than I am. He's an old man. He don't need--but he's wealthy. You know where he lives? Way up on those hills. He's got a swimming pool in [city]. A Mercedes, bullet proof, can you believe that? Glass tinted so you can't see who's in it. And he's (inaudible), and he lives in a mansion...

And he invited me into his house, a bum from the streets? I worked my way down. I'm just a common no-good-for-nothing guy on the sidewalk, possibly nickel and dime thievery, compared to this guy. And he takes me home to dinner 'cause he likes me? And he's got burglar alarms on this house. He's got dogs that are meaner than anything I've ever seen. Pit bulls and Dobermans. He's got a guy that trains them and he lives there in the backyard in a little guest house...

And I'm talking about a product, a member of this society up there where they go to these meetings. And he's laughed at me. He said, 'Jack, they want me to vote on these tickets you put on bumpers so you can park there.' He said, 'Fuck it.' He says, 'You know what? I can park my car anywhere I want and that cop never bothers it.' He said, 'I put that ticket on and I parked one block off the limit, and I got a ticket. And I went downtown and they threw it out.' I said, 'What happens if it'd have been me?' He said, 'You'd have got an eighty dollar fine and maybe towed your car away,' and he laughed. He said, 'This world's sick.' He said, 'These squares make me angrier every--'

I said, 'How do you think I feel? I said, '____, you know, I'm only 49 and I've seen a lot. I've seen a lot. I've done a lot. But I've never had your lifestyle. The more I see it, the less I want it.' I said, 'I'll volunteer.' He says, 'You are... crazy! You're drunk in the head.' ...I said, 'But I can look in the mirror in the morning when I'm trimming my beard.' He says, 'What? And you can see the gray and see your hair that's missing? I can buy you a hair transplant.' I says, 'Yeah, you could also buy me a casket, if I got involved with you.' He wanted me to get in, work with him. I said, 'I love the money but it's the taxes I can't pay.' He said, 'I don't pay taxes.' I says, 'Yeah, I know.' He doesn't pay; he gets around it legally. Not that he beats them like Darryl Strawberry, where he just from signing autographs and some little knickknack he didn't report, he's going to do 18 months. If I did something like that, I'd do 18 damn years. And I'd be 70 when I walked out of prison, if I walked...I'm lucky I bought this aluminum cane. I'll tell you, 'cause I had one that broke. Those wooden ones. I can't use it. I was too heavy. And I-- anyway I'm getting off.

So this man wanted me to work for him. All I'd have to do is drive his car and stay near his house and he'd go pay me a grand a day. That's not too bad. Treating me, *wine me, dine me, all I have to do is chauffeur. He liked me and I'm a good aim with a gun. I had training. In my youth, I was mean. I didn't kill people but I, I can hold my own with the toughest. And especially fighting, I'm an animal. And I'm not proud of it. It hurts me. When I do it, I don't get any-- thrill. Even if I'm right, I don't...*

The subject of Jack's idea for a "place" comes up again:

Jack: Well, what would you think I would want? You know you'd have to have a--a barn that would accommodate the people. And there's no way to control it, lady. There is no way. There's no way possible you could do it.

But you're never going to have the money unless you go talk to my friend [the Mafia man]. He would buy it. He would donate it to help these people. He came up like I did. Just like I did. Little better and a little worse. But, I mean, just like I did. And he's a guts 'n'--that's all he is like me, you know? He said he idolized me the other night. I said, 'Are you out of your mind?' He said, no, he said, ' You got promise, you know?' I said, why? 'Just 'cause you do what you believe and you don't care.' But I says, 'Yeah, it's a good thing I don't believe too much, huh? I'd get in trouble quick, you know that?'

But you could never get the funds. And you would never get anyone to work there. You know. If you did, they'd be in it for two things--the money--huh?-- and the power play. Some people like that power. Tower of power. 'Cause in reality, there's no rewards for helping people. Do you think I get money for doing anything around here?

I have three kids that are grown up and I'm still helping them. Can you believe that?

Int: Talk about your kids because you sort of mentioned them last time--

Jack: (softly)No, I'll talk about them some other time. They're good kids. I don't get my family. That's all I got.

Int: Are they around here?

Jack: No, they're gone. They're in college and they're doing real good, and I'm proud of them. I wonder what's wrong with my son. I wonder what's wrong with my daughters. But, there's nothing wrong with them. I just raised them as different as I am from night and day. And I worked--

Int: What do you mean?

Jack: Well, they never had to steal. Not that the opportunity is not there. But I remember I worked two jobs and stole on the side just to keep them in school, fed, and their $100 sneakers didn't bother me. But I wasn't living like I am now. I was dealing in drugs; I was fooling with the lifestyle, and it hurt me to do it. And if it didn't hurt someone to do that, or if they didn't have some kind of conscience, they're not human beings. That's a fac--that's the way I feel. I don't know. Maybe I'm wrong. I don't care if I'm right or wrong. That's the way I am. And that's the way I'm going to be. This thing I wanted, my kids, I'll talk to you about, or, maybe later. But I was going to finish with this place.

It would be like that day room down there.

Int:. You mean like the ER lobby?

Jack: Yeah. But you would have people--well, why would they even want to come there? Just to eat? Well, hell, they got dining rooms-- you know? But sometimes they have to turn people away now to eat, you know that? Yeah. That's happening now. And some people are going through three times...all the tough street people that are... corrupt dealers. They're getting to be fed four or five times. They're taking home steaks like that, that they're cooked in the back; it's under the table.

You, as a winette for the day, I ought to take you on a run one day with me and the street vendor. You could write a book. And you would; I know you would...

The conversation shifts and Jack mentions getting out of prison.

Int: What did you go to prison for? I mean, you don't have to tell me.

Jack: I burglarized, uh, a pharmacy, doctors' offices and pharmacy. I was an addict. And I did many of them. I made a lot of money, too. But I wasn't in it profiteering in it. I was sick and I was profiteer-- And I was greedy. And I looked better. My family did pretty good. My kids were going to go to college. They were not going to scramble like I did. And they weren't going to have to play the, what is it? Get a scholarship. Be queen for the day? Come on, man, money walks. Bullshit talks. You either got it or you don't. And that's what this world is all about. Tell me different. Show me anything, any way that it's not based on, built on that foundation. Power and money and who and what you know. Well, did I know a lot. And I know <u>*good*</u> *people, too. But I used to know bad people that had more power than the good people. And my kids* <u>*went*</u> *to college...*

Back to this program, this place. It would be nice if you could just have one of those buildings, these gray, brick things. Just a whole --wards; you could put 100 people in there. But let's just start with 50 people that wanted to detox... What I'd like it [the place he envisions] to have is a registered, a LVN nurse, a nurse's assistant and a God-fearing doctor who eats Wheaties in the morning, has a hamburger at McDonalds for night. And goes to bed after eating popcorn and watching TV with his wife and kids. But I'd need this doctor to be sincere enough to think that these people are sick and [just] because they've injected drugs, probably have HIV and about a year or two to live, that they're still <u>*human beings*</u>*. And whether or not they've jumped or attempted to jump out of windows, or hurt people. And I'm not saying that it's all right to do these things. But there are people that I still don't like them, I despise them, and they've never done anything against the law. Do you realize that? I mean, they haven't been caught. Let's put it that way. But I would need a doctor that believes in what he's doing, and believes* *in human beings, not just in society. And that's why there's nothing to it. Because unless you play bureaucracy, you're playing with the politicians. And you don't play with them. They play with you. You do tricks for them and that's how they manipulate and that's how come, someone above's manipulating them; it's just that chain of command.*

Int: So there's no hope?

Jack: Oh, I didn't say that. It'll happen but when it does you're all going to be so God damn afraid. Half the country is going to run one way and the other half is going to start applauding-- because they're starting to snap now. They're just starting to. I watch people.

When I saw that Newt Gingrich, I call him Fig Newton--When I saw him talk about that orphanage and I threw that coffee cup, that was about as childish as I'd acted in about a week. But, I mean, I really had an anger. I didn't know I still had that much in me. But I know I got a lot in me! I'm not going to bullshit you. I got a lot of grudges to this day. But I've never been so God damn furious at one human being like that for a comment on television, for me, to do something like that. And I meant every stroke of it! (laughs) There was not one doubt in my mind that if that man had been there, I'd be in jail for busting his face. You know? Every bit of anger I felt for many years about orphanages and the way they treat kids today, and adults! They treat them the same way now. I'm not lyin'.

This gal [at his hotel] is--she's a lady of the evening. But that's the only kind of work she can do. By God, she's clean, she's careful, and she's good, and she treats me decent. You know. And she doesn't bullshit me. So we go and have coffee together. She comes down to my room some nights when she can't handle her life anymore. And we sit around talking, you know. I mean, for a lady of the night--she's only 30 years old. Nice *looking, intelligent person. She spent most of her life in a mental hospital. She's one of Reagan's rejects, you know.*

Uh, anyway, what I'm saying is, it would take a doctor and a nurse like her. She is an LVN. This lady I'm telling you about. It would take a nurse like her that's been through the ropes. It would take an EMT, or a guy like me, a nurse's assistant or something, that have been through the ropes to work with these people because--

Int: Do you think it does take medical people?

Jack: At first, yeah. At first. Not psychiatrists. Not supervisors and all that. You need a doctor to prescribe the medicine. That has the balls to prescribe it as it's needed for that patient. Not the hospital regulations...

It's politics, man. It's not even politics. It's like I said, money walks. And with money, you can walk around. And bullshit talks. You got to have some goin' for you. You got to have money and you got to have power. To have power, you've got to have money. What is money? Power. And the way they control you--I don't know how people can go to work every day. I used to look at them. I'd pity them. And it's getting worse every day. I see them and I feel sorry for 'em.

Int: But now, Jack, you know, today, you sound, well, you sound more despairing, to me, in a way--

Jack: What do you mean despairing?

Int: I guess you sound more like, uh, I mean, I guess my question is, but there's still something that gives you hope.

Jack: Oh, I've got hope. I do!

Int: And what is it?

Jack: I feel better than average today. I slept good last night. I was thinking about what we were going to talk about, and what I was going to try to say, which I haven't done at *all. But, you know, but that's all right because I didn't want to sound like a roving maniac or one of these assholes you see on television.*

Int: Oh, you never sound like that.

Jack: No, but I do, 'cause I don't like a lot of people's ideas. I don't like the way the system is run, but I couldn't run it any better... But, lady, it's worse every day. And, as you might not know, but I'm going to just give you a red tag alert. What do they call it? Code Blue. We are in a world of God damn problems here... I'm talking about our country. Our kids...

But, anyway, I--I want this place--it would be like a detox. And it doesn't take three days. It takes as long as that patient needs (shouts)! Do you understand that? It isn't, 'well, you got a 72-hour detox. Now, go save 'em.'

It was 72 hours before I could even sit up in bed, much less get out of it! I was shitting, I was urinating, I was pissing, I couldn't walk. I mean, that was out of it--even before my legs were bad. Your muscles are so--you're going like this and you're shaking. That's just from the alcohol. Can you imagine what it's going to be like, with narcotics, crack cocaine, which is another mind cripplin' drug? The guy who invented that should have got along with Hitler real well. I've never seen a devastating drug in 45, 46 years, I have never seen a drug as damaging as crack cocaine. And I've seen every drug, almost every drug, that they have.

And I would like to see this as a clinic--

I would need to have patients' consent, whether they had MediCal, Blue Cross, Red Cross, or Blue Shield-- I don't care. They would be treated the same. And I don't mean substandard. I mean, they would be treated as a human being...

Yeah, this would be where they would be treated as a <u>human being</u>. Where the doctor would say, 'Look, buddy, let's be honest. The bullshit's still in the game. We're *still going to play but we're going to play by my rules. My name is Dr. Jack, and this is my nurse, Ruth, and we're going to help you help yourself. That's the way the ball game goes. We're going to give you medication for withdrawal. And if you want methadone maintenance after that, that's fine, but we're going to detox you to a level where you're competent of what you're doing, physically able to handle the amount we're giving you so that you're physically able to carry on in life. And now you're thinking, what are you going to want me to do? Carry a lunch bucket? Screw you. I just want the high. We don't want you to carry a lunch bucket. You want to be able to use your mind so you're not devastated by an overamount of, of methadone,' or whatever they'll use. They'll probably use cyanide because this thing is so far out there.*

And the doctor is saying, 'We'll withdraw you, we'll keep you comfortable. You're not goin' on a ride in Disneyland, and this is a hospital and we're treating you, not mistreating you. You know, and you can get kicked out for smuggling drugs or alcohol or other consumption of, by giving , or muscling, mark--, you know, marking your pills and start taking them all and selling them to another guy so he'll have cigarette money. You know, you're not going to play any games on me.'

Int: So there'd be rules.

Jack: Oh, yes! And strict ones! But you play by the rules. See, they got rules here too but they don't bullshit. And I'm sayin', and if you get caught, not taking your methadone, or your tablets, or you're palmin' one, you're gone. And you're not coming back, you know.

Okay, now you'll be fed... Let's say, you know, where you have three balanced, well-balanced, more than you need to eat meals. But also we're going to have some therapy. And this isn't (inaudible) bullshit, or bush therapy, as I call it, where you can *just sit and bullshit your way into never-never land. You're not going to solve all your problems. You're not even gonna scratch on them, but we're going to start working on your foundation. And that's all you're gonna do, probably for the first 4 months, 5, 6 months. That foundation is, how do you want to get well? Do you want to do it, do it like all at once? Just stay off drugs and alcohol? Do you want to just go to a strong outpatient program? That, you know, like--I don't know, these [rehabilitation programs]. I'm not a program man. I did it by myself; I--. To me, they're just prison. And they're a moneymaking bullshit and son of a gun. But I do know some people that have made it.*

Int: Oh, but then how will this be different from other programs?

Jack: All we're doing here is physically getting them ready. What they do with it after that, that's up to them. I'm not a doctor, a psychiatrist.

Int: Okay, okay. But you're saying it could be 6 months. It could be even longer.

Jack: Here?

Int: Yeah.

Jack: No, no.

Int: Oh, not here.

Jack: Well, I'd <u>like</u> that. It would be beautiful. They have the space right over there right now, you know. They'd have a waiting list from here to New York. (chuckles) Ain't lyin'! They would. But can you imagine that? That would be the most beautiful thing God could ever wish for me. I'd die for that almost, you know that? Six months-- you could help someone, <u>really</u> help them. I'm just trying to get them off the street so that you're not still standing in line wondering where you're going to go next, what you're gonna do. I'm just trying to help some sick guy that's is as slick--not as slick as me--but sick, but has reached the end of their rope. You know, they're tired. Not rope to hang himself, commit hari kari, but that they're sick and tired of being in the street. They don't know what to do. No one will listen to them. They need help. They don't know where to *go. They've played, been, they've played games, got caught, so they've fucked themselves, literally, with the system. There's nowhere else to go! (with intense feeling) What do you think half these ODs[overdoses] are? For God's sake, man! You don't get a man or a woman who's been shootin' dope for 5, 10 years, that is so damn naive that they're gonna try to do a 60 dollar amount of heroin when they've got a 40 dollar habit. You don't see them shooting a speedball like John Belushi, partying with a hooker, laid up in a motel room. Usually you find this OD in a rat trap hotel with lice and rats running around the son of a bitch, with a rig still in his arm. You know, he's reached the end. Half of them, I believe, are almost like a suicide. It's the last straw. (softly) They're goin' for the big sky, the big lie, the home run. I know. I've watched 'em.*

Jack tells me about a painful personal conflict he experienced during which he was tempted to resume his former life:

Jack: I took a couple of weeks off, a couple of days. I wasn't feeling good anyway. I went out with some buddies of mine. But these are, like I said, these are gangsters. And I took a good look at what their life is and I took a walk by myself, bought a pack of smokes, bought a half pint of whiskey, went to my favorite place near the park, by the grass... I sat there and sipped--

I'd think of all the years I was alive and I started feeling sorry for myself. And then I thought man, I'm playing right into the same old stuff. Poor me, screw them, they're all against me. And then I thought these people that are wanting to help me now are no better than the ones that I'm mad at. But actually I respect the gangsters more than I do the ones that are squares, you know? You don't believe that or understand, but that's just the way it is, and it's true. A lot of the--[gangsters] are better people than the squares. They've got more courage. They do more help for the poor and the homeless and the hungry than these bums that sit around here making paychecks.

... I still do that once in a while. I never quit drinking. I don't drink every day. I don't drink to go after work to relax. Cause I'd need it every day then; I'd have to relax 24 hours a day. Why in the hell get involved to have to get un--to have to relax. So I'd have to quit working. I'd have to quit, quit trying to be a human being. That's a lot of work! (chuckles) You know. But once in a while I like to get a pint, half pint, sit down and enjoy it. I don't get sick, if it didn't bother me, I guess it's all right. I never promised anyone or I--no one ever asked me because they gave up even trying to think I'd stop. You know. I never quit but I, I, I did at first. I quit until I was well enough to know that if I took a drink, I could get that sick again. And then I realized my body is like anyone else's. Some people can drink and they like it. Some people can drink and they don't like it...

I mean, I feel good by helping someone. Maybe--you know, no one seems to understand that... maybe you would just being a nurse but I'm not a nurse. I mean, I've given a person a pair of God damn clean jockey shorts and a pair of socks and they're tickled like they've just received the Pulitzer Prize...(chuckles)

No, but, I, I think, I give them a smile. I mean, I talk to them like they're human. I don't throw them to 'em like they're a piece of dog meat and I've got a kibble for them. I treat the patients, the people who are coming in to see-- their parents, I treat them as if they were my parents looking for their kid. I'd be kind of upset. 'Where's my son?' 'Oh, I don't know.' Is that what I'm supposed to say? 'Who gives a God damn?' I'm trying to find this lady's mother, you know. Like who am I? You know, but everyone is important. When their kid's sick or their mother or father is lost in this [hospital]...

Can you imagine walking in here and knowing your mother or father had a stroke or a heart attack and, and you don't know where they are and I can't find them? You're going to be pretty God damn upset, aren't you? So I have to use a little diplomacy down there and convince them that their father or their friend or loved one is all right. And *that it's not the way this place is run, although 90 percent of the time it is. (chuckles) But I find them. I'm good at it. I know they've got to be in either intensive care, coronary care, or the coroner got them. Now, I don't want to say that to them.*

I've seen guys do that! 'Well, if they're not here, they're either dead or they got healed and walked out.' You know, that's exactly what the guy said. Now, I damn near hit him myself, but I, I, I know I was very upset. I walked out and then I turned around and then I turned back around. You know, I was spitting nails. But I swore to God I would never be like that no matter how you pushed me, or what you called me...

Int: So what do you do now as a volunteer?

Jack: I work the front desk.

Int: You're not doing gurneys anymore.

Jack: I can't. I could. I'd like to but I'm afraid to now with my back [he fell and broke his coccyx not long ago]. And my legs are too wobbly now. I know they're getting worse but I don't admit it. But I bullshit myself. At least I know it. But if I give up, I'm giving up, and I don't give up lady, you know me. As you know, I just--(laughs)...

And I do that. I do personnel. And then I got my program that I work. My little volunteer--. I go to [unit]. I work, uh, I don't work! I volunteer. See that's the difference. I don't get paid. That's the only difference. I work harder than the employees. I go to talk to people about their AIDS. I've studied it. I've read some books on it. And they're less informed than even Mickey Mouse and Donald Duck. 'Cause I've learned from, uh, ____ ____ who died in my arms in her home, and her Mom was right next to me. And people who have passed away from it, who have just got it, I found out. They told me how they felt, I watched their expressions, I held their hands. (softly) My hand, the skin didn't fall off. Look at it. (chuckles) I might use cream on it and that's from this soap this cheap hospital buys. But, you know, people like to be liked and loved. And when you're sick like that and their own family throws them away, what do you *think? Do you think they don't like me? Come on! And they--we play cards. I never thought I'd play gin rummy on the streets, much less as a volunteer in a hospital room for free.*

But this gal [Faith] is dying and she likes to talk to me and I bullshit with her. No-- I'm not bullshitting. I'm, I'm-- just sharing. I got a whole bunch of days left, I hope. I could drop dead tomorrow and still feel that I just crammed in a lot of beautiful life, by God and whatever else makes this whole contraption work. But I'm sharing with some one. Why not? No one else does it, but that's all right. Some people do it their way. I just do it mine. I have the time.

I can live on 600 bucks a month. It's not easy. Believe me, I'd like to get a few more dollars just to supplement my income but they--didn't hire me. And that's okay too, I'll--

Int: You applied for a job?

Jack: Yeah, a couple of them.

Int: Tell me about that.

Jack: Well, I tried to work with a TV company here. They were going to hire me but then they started losing business. And it just--I don't know what happened. She never called me back. I saw her once or twice. She's based in Louisiana. I don't have an outstanding work record, for Christ sakes; I'm almost 50 years old. I worked as a disc jockey. That was the most wonderful job I ever had. If I had a talk show, I'd probably beat Donahue's ratings, but-- That's just a fact. That's what people have told me that are into broadcasting. But that's not what I want. I could go work right now at [radio station]. ___ ____, the manager, called me three times. Oh, and I have my own phone too, I forgot to tell you; even though I'm in the skid row hotel, I got a telephone. So, you know, I got my little--it may not be the best car or telephone, but it's mine. And I built it *myself. I got it. You know, that's what makes me feel good. You know, that--little things like that. Not that I'm better than but instead of buying shoes, I did get a phone.*

And my bill is high because I let other people borrow it and they snuck toll calls but that's stopped. And I fried his bacon. I, I scared him to death. I was going to clean his plow, man, $35 calling Utah, Michigan, yeah, . I don't know. Some God blessed place I never even heard of. Talked for an hour and a half, well, I had to pay it off. I thought he was talking local. It was Christmas, before Christmas; I left, I went to the store and I bought a barbecued chicken and, uh, made a nice little--I have a hot plate. I attempt food poisoning. Heh! Gettin' almost as good as these guys here. And I have repeat customers. (inaudible) if you don't chip in. It gets kind of expensive but I make a nice meal. Uh, it's unique.

And then he ran up about a $70 phone bill on me. So I'm paying $20 of that off a month. What am I going to do? Kill him for it? I almost kicked his ass. The guy was as white as this wall. And I felt kind of proud about that. I didn't have to hit him so I just told him, 'Look, man, don't let the sun set on you around me. I'm not kidding. If I were you, I'd get another hotel to live in 'cause every time I see you, I don't know what I'm gonna do next. And I'm being honest with you.' I said, 'I'll tell you what. You pay me $20 a month out of your check and I'll put it on the book.' He has not paid me one penny. He moved. And he laughed about it to another guy. So when I see him, I'll deck him. No, I won't. I should but I won't. But, I mean, it hurt me, too. But then when he laughed about it--

Int: Well, when they take advantage of you like that--

Jack: Well, they do but that's, that's the problem with bein' a square. That's the trouble with being like you and not doing it, but knowing that they're doing it to me. I mean, I read right through the games.

Int: They wouldn't do that to you if you were using again or--

Jack: No, because I wouldn't be kind enough to let them.

Int: Ah.

Jack: Or I'd've cleaned his plow as soon as I heard him talking Mom and Dad, it entered my mind right then he wasn't talking to someone around the corner. Snow on the ground, you know. I should have just whomped him right then. And bellied him up. But, you know, I said, well, it could be--ah, it's bullshit, Jack, don't worry. Just do what you think is right. And I was right. 'Cause--

Int: So if you're going to be straight it kind of means you have to steer this course between being--

Jack: Well, that's my rules. Now what should I be, an asshole, a card guy? Sylvester Stallone? I don't need that, and I ain't no Fats Domino. I ain't gonna wail--. And I'm not going to cry about it. But I handled it. But I didn't get myself in trouble about it either, which I could have very easily. And I'd a had a nice reputation. Boy, he's a bad son of a gun. He creamed that M, he knocked out his gums. He didn't have any teeth but I knocked his gums out. You know, and I would have!

But I'm not looking for a reputation. I'm looking to live my life the way I want without being in trouble with the law; feeling good, basically, and having people feel good around me, you know. If they don't say, God, that guy's an ex-convict, and he-- You know, now that's nothing. Hell, they got guys--there's hardly any one around here ain't been to prison now. And-- that I'm square--not square. There's nothing wrong with being square. That he's just an honest guy, kind of loose, kind of lame, you know. Someone bums a quarter from me, you think I track them down? You know, here, get something to drink. It's your liver, you know, that's the way I'm thinking. God, I'd sure like to go with him. (laughs loudly) You know, I could. That's a difference. Now if I want to go have a *drink, I'd buy a little bottle but I drink it in my room. I drink it in a, at the beach or something like that. I don't even, I used to do that first, and I don't enjoy it anymore. Even socially—that's what I call social drinking —or relax, you know, like on Christmas, you know, I had one beer and I started feeling bloated. So I said, I like root beer better 'cause it's sweeter. And I put ice cream in it (inaudible) that's why I lost a lot of weight. (chuckles) But that's, that's my thought. So I can either have a fat ass root beer float or a beer. Now, which one would you rather have? And some people would say both. Well,-- Okay, but that's what I'm saying.*

And, I mean, I can drink if I want. I don't have the money but I don't need money, I could get it. Or drugs, you know. It's a very easy thing to get...

I ask Jack if he thinks other people would find the same intrinsic value in volunteering that he does.

Jack: Well, each person would get what they put into it. They could get what they get out of it. A lot of people get just what they want out of it by just taking and not giving, and they don't feel a God damn thing, of guilt or happiness. That's the ones I feel sorry for. At least if I could feel sorry or useless or guilty, you know, at least I'm feeling <u>*something*</u>*. I forgot what it was like to feel good or to give instead of take. Because I knew the* <u>*system*</u>*. It's hard to reverse. It's very hard.*

... I don't feel like a chump. I feel I'm doing it my way, with their rules, plus my rules. I got more rules about right and wrong around here than they do, and ethics, and feelings, and boundaries. Not getting involved with people. Not just socially. Like this girl I know here [Faith]. I've known her a number of years. I like her as a friend! You

know, I really like her and she's going to die and it won't be too much longer. And I know that and she knows that. And we don't even talk about that.

I mean, I don't know. Makes you want to jump out this window or something. It looks so much better. But I know she's going to pass away and I'm going to cry. And we'll probably cry together, you know, before she does. But she's worth it to me. (pause) (choked up) Who else cares? (pause) (tearful) Her own family doesn't come here.
Int: Her family?
Jack: Do you blame them? Do you blame them? You don't know the situation. How could you? But I know her. I know her family. And they're both wrong. (chuckles sadly) How's that for honesty? But I'm not wrong. She never had an espresso before today. I bought her her first espresso. I felt like a lottery winner, you know? Made me feel good. Plus she likes my cologne. (laughs) ...

The conversation shifts to what Jack did yesterday:
Jack: *I went and worked personnel yesterday. Instead of getting out at 2, I stayed until about 2:15. Then I was tired, and I went home. Took a shower. Turned on the television. There was nothing really on except for on [station]. I like that kind of jazz. I relaxed. And a couple of friends came over, one at a time, bummed a cigarette, you know, and just talking. One gal that owed me two dollars paid me. So I was able to get a pack of smokes. You know, things work out. I'm not doing this for any money but I get my reward. I went home. I felt tired. I felt like a--just human. What does, quote, "human" mean? I'm sure if you have a good day at work, you go home, you feel kind of good. You have your husband, children or whatever, you know? I don't. I've got me, and a hotel full of lunatics. Some of them are worse than others.*

The other day I saved a guy's life. I was, I came home from work again. I was here all afternoon. At night I had a night clinic. I had night court with my doctor--that's what I call it, night court, with Dr. H. And I got home about 10:00. I was watching the news. I went over to Katy's house. And her boyfriend Allen made me a scalloped fish sandwich and some chicken noodle soup. Because then, again, I missed my dinner here. And I was hungry! And I don't have money to go eat out, you know. And what I had, I had to loan it to my son. I gave it to my son for spending money. He's kind of screwed up right now (voice drops).

But--, anyway, I had a sandwich and soup. And she gave me a couple of smokes. And I went home. I was getting ready to go take my shower and (bangs 3 times), 'Jack, Jack.' 'What? Damnit, what's wrong with you morons? Stop it, man, just knock!' 'Jack, Allen's dying.' I said, 'What are you talking about?' 'He OD'd!' Well, I don't run. Even for an OD. I grabbed my cane and I must have looked like something out of a cartoon. But I got down the hall from here, just a little past the elevators, near where he stayed at the hotel. And he did. He OD'd. He was dead. He was blue. I couldn't get a pulse. I couldn't get a carotic [carotid pulse], you know. So, screw it. Blue-- I mean. I --I made a seal, gave him CPR, and he started coming around.

Then the police came because someone--they finally got 911. I have a phone. I called too. See, 'cause they're too God damn stupid to go phone and do it themselves. So--I-- But they called too. I yelled at them, 'I didn't call 911. I came running, when you said OD; I figured you called them before you came and got me!' I'm doing this in between breathing and trying to give him his heart on the bouncy ass bed. I didn't even want to stop to put him on the floor 'cause he was stiff, you know. And they're all in there trying to steal his flute, his little money on the dresser. And I said, 'Get your God damn asses out of here, <u>now</u>!' And I'm mad and I'm watching 'em. I'm not dumb; I'm slick. I'm slicker than --and they were (inaudible).

And then the cops came. They came first and I said, 'Hey, Gallahad, give me a hand, will you?' He said, 'Do you know CPR?' I said, 'No, I'm kissing the sucker, man.' And he laughed, and I said, 'You do the chest, and I'll breathe, okay? Go.' And I was resting. You know, I'm not a--I get involved too, you know. I have feeling. And he worked the heart and he stopped and I'd give him some air. And then we worked together. Pretty soon I got a cough. I said, 'Keep it up, Ma Bell never fails, 9-1-1, huh?' And I'm thinking, get outta--and then the damn people left 'cause the cops are there. And the firemen came and intubated him.

And I said, 'Thank you, Jesus, let me out of here.' (chuckles) You know, I don't need these cops and firemen, paramedics. I was shaking a little, you know. (Yeah) And I --huh! I knew I wasn't gonna sleep.

That was Tuesday night and then I came in Wednesday...I didn't eat breakfast. I was gonna miss lunch so I had a sandwich, orange and a milk, which was nice. I had a little picnic down here by my favorite entrance way.

And, uh, the guy lived...

Int: Wow, Jack, that's just really quite a story.

Jack: Yeah, that hap--that was my Tuesday night. And my Wednesday. So that's why last night, I was tired when I got home. And I got to borrow some money. I'll get some. Maybe from Steve. He gets paid--today's not Friday. He gets paid Friday. One of the few people I know that has a job that's been like me. But he's got a profession. I don't have a college education, you know. I got a street education. But he's got a job and he's --computers. And then maybe Friday he'll loan me a couple of bucks, to tide me over. And, you know, that's-- But he works five days a week. He still uses. But he's on methadone and he smokes crack 'cause it enhances it. That's his problem. It's not a *problem to him. He functions. He's happy, you know? He's content. That's another word they don't ever use.*

No one's ever content. I'm pretty content volunteering. I'm not sad I couldn't do better. But then I'd be probably in trouble with the politics of 8 to 5 jobs, or, you know, having to satisfy your supervisors. And the money aspect would interfere with their rules and regulations. But like just the little job I do there[at the hospital], I could do that for 8 hours and get paid for it at another hospital. And I should try to go about-- then again, I don't know how to go about getting a job like that. I'm kind of crippled in that way, too. Not just my legs, you know. But I need to find something. If I (inaudible) the cost of living is high rise. And I'm living in like a hobo on grounds. I'm living in a dope fiend hotel, and not using drugs. I'm not hustling the money, which I could do real easy. It'd be easier than going to work, and I wouldn't have to do anything really.

So, it's tempting to me. But then again, if it was [really] tempting, you know I'd be doin' it. If I wanted to, I would. I just don't think it's right. That's why I don't do it. Morally, I think it's wrong. And I am not the most moral person in the world. I've done many things I'm now sorry I did. Not ashamed. I think I was a very foolish person for doing them. And I'm sorry that I did 'em. But I made my amends to the people where I could. That's part of recovering, in alcoholics and drugs anonymous. But that doesn't change the fact that I did them. And I know I won't do that again to people, or get in that position. And that's what helps me. People like [nurse]. People like a couple of the nurses back there. ____, she's an LVN. She just started 6 months ago. For 6 months we had dinner almost every night. I'd come back for dinner. I'd catch the 33 and she'd be on it. And I'd go just because she was on it, even if I wasn't going to eat dinner. And she *became a good friend. And she's got a--of course, you'd have to meet her. She works 5 to midnight till 1 in the morning.*

Int: Oh, what a shift.

Jack: I know, but I love her. She's nice. She's funny. And I was thinking about maybe having a relationship with her. Then I was thinking, she's got enough problems, she don't need to hang around with me. You know. But, and then she's working crazy hours. And I don't like to get involved with anyone where I'm working. That's something else that I don't think is too cool. Even though I'm not working. But, in my mind, I feel that if I got to go out with someone here, started dating them or something, I--it would be too much for me. And I don't do that much dating. I got a couple of girlfriends and they're hookers, for Christ's sake. One of them is a hooker and one of them is just a model, but I don't know what she's doing on the side, you know. But they're nice. One of them I like. And, and, that's about as far as I think it's going to go. I like this girl [Faith] too, for Christ's sake. I really liked her for a while back there. And then, not because she got sick, but she was using, and I wasn't-- I wasn't seeing her every day. But she's a kind person. And the only people that come up to visit her are other hypes [drug users] and all they come for is to see if she can give them, you know, or just get for 'em, or score for 'em; you know, it's sad.

And I like her. That's just the way that ball game is. And I can't help the way I feel. But I won't get involved until she gets out of here. Maybe we'll go out to dinner, you know. We're not going to run off and get married; with her physical condition, I don't know if she'll be alive for 6 months. I don't know. Bone cancer, my God. But she never snivels. The heart of a gunfighter; I respect her for that. You know. It's sad. She's only about, I don't know, 32 years young. And never complains, not once, to me. That's pretty rare, huh? Makes me feel proud just to know her, huh? (pause) Yeah.

CHAPTER SIX

LEGITIMACY

Jack: I mean, it's painful enough to be broke or little or no income. When you're sick, whether it's mentally, physically, or even if it's just in your head, you think you're sick. And if someone doesn't treat you, you know, take *__heed__* *to it, and if you're having physical or mental or* *__bullshit__* *pain, it —it's real to that person; it was real to me. God damn, when they treat you like you're something else, like that garbage can over there, they react. I don't care. Even a* *__dog__* *will get mad if you don't pet it, or if you kick it.*

***

Nurse: [He] couldn't walk very good, which actually was a good in for him 'cause he, you know, he definitely had some, you know, *__real__* *medical problems.*

***

Nurse #1: Whenever he gets drunk somebody thinks there may be something really wrong with him.
Nurse #2: That or if he doesn't get drunk enough, he seizes.
Nurse #1: Yeah, he seizes if his blood alcohol goes below 200.
Nurse #2: Probably, yeah.
Nurse #1: Last time he came in, he came in because he was hypothermic. He had a temperature of like 32, 33.

Introduction

This chapter is the first of four which focus tightly on the "micro" level: the everyday context of the emergency department itself. In this chapter, providers and patients alike reveal strong moral evaluations in narratives which emphasize blameworthiness and issues of control and authority. The role of economic pressures in creating clinical situations in which patients for whom the "system" cannot provide a "quick fix" are viewed by clinicians as adversaries is linked with the acute care and high-technology bias that renders low-tech needs invisible or problematic.

Commonalities of "Frequent Flyers": Chronicity and Unfixability

The patient participants in this study were, as will be apparent, not all alike. For some of them, a visit to the ED only took place when someone else, seeing them lying on the street or seizing, called an ambulance to take them to the hospital. Others regularly initiated their own visits for a wide variety of ailments. However, almost every one of the patients I interviewed shared two commonalities: they all had conditions not readily "fixable" by immediate medical treatment, and those conditions were interpreted by providers as more or less illegitimate reasons for coming to the ED.

Their conditions included "chronic illnesses" such as alcoholism, drug addiction, asthma, mental illness, chronic pain, and seizure disorders; and social disorders, such as loss of or abandonment by family, family conflicts, or breakdown in caregiving arrangements. Sometimes these were initially obscured by more immediately "fixable" problems, such as traumatic injuries, but more deeply-rooted problems lay beneath these in almost every case. At least six of the patients identified by providers as "frequent visitors" were not, in fact, frequent visitors at all, but because they presented with complaints considered to be "inappropriate" or illegitimate, they were generally regarded as being in the same category. For example, a 41 year old man who checked into the ED with a presenting complaint of "chronic back pain" was referred for my study by a doctor because the patient had returned "several times" with the same complaint; however, examination of the medical record revealed that the patient had only been seen twice during the past one year. (The patient was later discharged with a diagnosis of "chronic back pain.")

Kirmayer (1988) has pointed out that

> the threat that unexplained or uncontrolled sickness presents to the authority of biomedicine is neutralized by making the patient accountable for the illness. Patients are either rational but morally suspect in choosing to be sick or irrational and thus morally blameless but mentally incompetent (p. 83).

One nurse captured this understanding in talking about these ED "regulars" :

> *Nurse: I think all of the regulars are sort of on a self-destructive mode to some degree. They don't like having their disease; they don't like taking their medicine;*

> *don't like seeing a doctor on a regular basis so that they get their medication. It's just--I can't think of any regular that, uh (pause), that, that doesn't participate in their reason for being a regular. Very, very few.*

Legitimacy and Blame

Provider Perspectives.

Health care providers in this study maintained a constant discourse about what was "appropriate" and legitimate and what was not, and concern with the legitimacy of the patient's complaint overlapped broadly with concern regarding the frequency of the patient's visits to the ED; the element of blame is critical in teasing out the distinctions between these two concerns. For example, patients with non-alcohol-related seizure disorders who came to the ED frequently were not generally considered illegitimate (and thus blameworthy) as long as their blood tests revealed compliance with the prescribed anticonvulsant medication, as the following observation shows.

During my fieldwork, a younger nurse timidly suggested that I might want to talk to a female patient she had just checked into a room. The experienced charge nurse, however, hesitated at this, saying, "well, but...she's [got] *seizures,*" suggesting that this excluded the patient from the category of frequent visitors I had said I was studying. The charge nurse later clarified this distinction by saying, "she's not really in your category. She has seizures at the bus stop and comes in; her Dilantin level is usually not even that low." [Fieldnotes]. Thus, for this experienced nurse, as for the doctor mentioned above, the "inappropriate" aspect of "frequent" visiting is primary and trumps the *actual* frequency of visits.

On another occasion, a nurse referred me to a patient she knew to be a "frequent visitor," the term I used to describe the population I wished to study. When I knocked on the door, the resident and the attending physician were examining the patient. I withdrew and they came out shortly. The attending held out his hand and introduced himself to me and I did likewise and explained what I was doing, that I was doing a study of frequent visitors and I was told Mr. ___ was one. He and the resident looked at each other briefly. "Well, but he's *legitimate* this time," they both murmured, almost at once [Fieldnotes]. The "problem" of heavy ED users, then, from the perspective of many health care providers, is not the frequency of visits but the problematic nature of those visits, with moral blame often central to such definition.

This at least partially accounts for the array of pejoratives used in referring to these patients. Such common labels as "abusers" or "abusers of the system," "repeat offenders," and "frequent flyers" give way to calling such patients "animals," "subhuman," or "nightmares," all terms used by health care providers in talking with me about these patients. Perhaps most aptly descriptive is a term suggested by one nurse, although I did not hear it used by others: these patients, she suggested, are "incurable recyclables."

Patient Sensitivity to Moral Evaluation.

The patient participants were likewise culturally sensitized to the moral evaluations health care providers made or might make in relation to them. A 76-year-old patient with asthma said,

> *I was just here last week or something like that. I was here for three days or something like that. Then they let me go, see. Now I'm back here again. I don't know. My landlady called 'em. [the ambulance] That's what it is. But I didn't want to come here.*

There is a subtext here of blame assignment; the patient hints that providers may be at fault because they "let him go," perhaps prematurely. At any rate, he seems to say, I am not at fault because I didn't come on my own. Here blame is clearly linked with volition and agency. An alcoholic patient brought to the ED by the police makes a similar rejoinder when I ask him whether he has a particular emergency room that he uses.

> *Int: Do you, is this a particular choice of your emergency room, or do you go to just wherever, if you have to go?*

> *Patient: No, no, I--hey! Damn it! I didn't come here by choice!*
> *Int: Oh, I know--*
> *Patient: Ask those fuckin' cops! I ain't no fuckin' beggar....Ah, they coulda just left me alone, I coulda lived out there--*
> *Int: You would have been happy to just stay out there.*
> *Patient: Damn fuckin' right.*

Here the patient's shame at his social circumstances and his helplessness in the situation are defended against by blaming others for his plight and arguing for his independence. As the next chapter reveals, this posture mirrors that of providers, whose inability to attain the ideal of omnipotent rescuer leads to feelings of helplessness and blaming. The moral emotions of shame, blame, and guilt call attention to implicitly accepted notions about the kinds of persons we are "expected" to be: independent, resourceful, rational and autonomous.

Illegitimacy's Social Meanings

Heurtin-Roberts and Becker (1993) suggest that chronic illness itself may be a biomedical construct. On this view, such conditions, which often "fall on the margins of healing systems" (p. 282), are potentially fruitful areas for cultural investigations, since they reveal much about the "hidden arguments" (Tesh, 1990) involved in definitions of many aspects of everyday life. The patients in this study are biomedicine's "limit cases" in many ways, embodying the failures of what Benner (1994b) has called our "techno-cure"-oriented system of medicine. In their apparent recalcitrance, these patients stand for individual and/or cultural resistance to medicalizing domination (Conrad and Schneider, 1992).

But these patients are also society's limit cases. They embody failures of families, of communities, of policies; they reveal the human consequences of our economic system's inability to provide a good life for all people. They force upon us all the ethical question of what a society--and what we as individuals--will choose to do about people who are somehow "broken" and cannot be readily "fixed." They also provoke, for some, deeper questions about what kind of society we share, and about why the cultural definitions involved in these "limit cases" are dominated by the discourse of power and control (Foucault, 1979).

Legitimacy's Social Meanings

Compliance as Legitimacy.

Compliance with recommended medical treatment is a necessary but not always sufficient condition for legitimacy. Noncompliance or "uncooperativeness" is often interpreted by providers as evidence that the patient's needs for medical care are less than legitimate. In the following story, a woman with an abscess from intravenous drug use describes a situation in which these issues are primary:

> *Sally: This abscess is now almost three, four weeks ...old. And uh, this one time, when it was in the first or second week of it, and it was still pretty deep and open, and hurt, really, worse hurting than now--and uh, I had to pack it and put the bandage on, and I had took the bandage off at home, in my hotel room? And um, I tried to get a piece off, and it was stuck to something like a nerve or something; it felt like an open--when you have an open nerve in the teeth--it felt like that on my leg. Right? And so I didn't, I couldn't get it off, and so I just put some more bandage around and left that half a bandage in there.*
>
> *And then I had to come for pain pills through here, to the emergency. And so I, they took me in, and I said, 'I can't get that piece off; it hurts too much!' You know, and they said, 'well, just do it real fast,' and I just couldn't do it, it was just hurting like hell.*
>
> *And so, they had scissors there, so I cut it off, so at the end, there was uh, like a piece as big as my thumb, a little square piece of bandage that was still stuck there, and I couldn't get off; all the rest I had got off, but just that tiny piece I couldn't get off. And he said, 'well, just rip it off like this,' and I said, "I tried, and I couldn't do it,' you know, it hurt so bad. And the doctor said, um, I don't know which doctor it was, if it's the same one who's on now, or if it was a different man, I can't remember exactly, but that doctor was very, not very nice, and he was*

> *going, 'I'm the boss here!'--he gave me three Codeines, three Codeine Threes, that's like one Four. And then, he did give me a pain shot of morphine or something, you know, after I said, 'If you give me a pain shot I might be able to do it.' And I waited twenty minutes, when it was supposed to be started working...and I st--it still hurt! I still couldn't get it off.*
>
> *And I said, 'I'm sorry, I just can't do it.' And he goes, 'well, if you don't get it off or let us get it off I won't give you no pain pills.' And he said, 'If you get it off I'll give you some Codeine Threes.' And I couldn't get it off. So he, he called the police on me, to take my clothes out to the ladies' bathroom, and I had to get, because I had this hospital gown on, and I had to get dressed in the ladies' bathroom, and back--even my bandage was --half off, you know, and put my bandage back on and stuff, in the ladies' bathroom, and he--first he gave me nothing, and then the policeman came with a piece of paper, and it was [a prescription for] some ibuprofen, and it was--the first or second week of it, you know, it was still very open and very deep and--it was still deep open and really hurting, but he wouldn't give me no pain pills 'cause I didn't let him take this piece off. But I didn't do it out of [maliciousness]...I, I just hurt so bad, I couldn't do it...And then two or three days later, I had to go back, it got back infected or so, it was hurting so bad, you know...and so they kept me another two days there, and they said, 'you have to soak it,' and they put--poured water...I poured water on that like ten times over, twenty times, and--and then I finally got it off. That little piece that was still there.*

Sally's "chief complaint," pain from her abscess, is initially viewed as legitimate by the doctor, and she is given a relatively small amount (for someone with a high narcotics tolerance) of pain medication, an acknowledgment of that legitimacy. However, as she is unable (or unwilling) to comply with the doctor's demand for removal of the stuck dressing, her ongoing need for strong pain medication is downgraded by the doctor and she is instead given a milder analgesic medication and excluded from further care. The discourse has deteriorated to one of power and control, of pure commodity exchange. Medication is offered in trade for compliance; when compliance is not forthcoming, whether from intentional or unintentional causes, the deal is off. Sally resisted compliance in two ways: by failing to achieve adequate pain relief from the medication she was given, and by failing to remove the stuck dressing.

But compliance, while a necessary condition for legitimacy, is not always sufficient, as in the case of some asthmatics (Becker, Janson-Bjerklie, Benner, Slobin, & Ferketich, 1993) who are faulted for having "waited too long" to come to the ED as they complied with the home treatments they had been prescribed (see "Medicalizing Control," below).

The ED as Context

Time Pressures

In an environment so imbued with urgency as the ED, uncooperative behavior means wasted time, time that may be needed to help someone else with a problem that can be readily "fixed." Providers in such an atmosphere are vulnerable to being overwhelmed and must constantly re-set their priorities as new patients arrive without warning; a kind of legitimacy thus also inheres to conditions that can be rapidly and definitively treated. A nurse admitted, "we're so jammed up with trying to be ready for whatever may happen that we want to get people out as fast as possible." Conditions which require more time to diagnose or treat, or patients who do not comply with treatment recommendations, are experienced as problems which disrupt the smooth flow of activity. For novice and advanced beginner practitioners, whose anxiety about their responsibility in the situation is overwhelming (Benner, 1984; Benner, Tanner, and Chesla, 1992), such problems quickly become sources of frustration and resentment and are reclassified as less than legitimate:

> *Nurse 1: It's, it's sort of hard to see on some of these people, it's like when you get the new interns and residents, they're young, they're fresh. They don't know these people. And the first couple of times that they see them, they are the true caring health care professionals who are attending to all of their needs in a professional manner. By the end of the month, they're hostile towards the patients. They're tired of seeing--'this is the fourth time in two weeks you've been*

> *here. What's wrong with you? What's going on'--I mean you see this change in them. And it happens in a matter of weeks, really.*
>
> *Nurse 2: Sometimes less than weeks.*
>
> *Nurse 1: Yeah.*
>
> *Int: And why? What's going on with them? I mean, is it just that they don't want to see these people over again?*
>
> *Nurse 1: Well, I think that they're--it's not that they don't want to see them. I think that they're--you get tired because it's very time-consuming. You spent all this time and effort on them two days ago, and they sort of say, yeah, yeah, yeah, I'm going to stop drinking. I'll try to get in a program and stuff like that. And then they come back totally wasted two days later. And it's like frustration. You see frustration levels climb on them, on the people. And it happens fast--*
>
> *Nurse 2: Well, health care professionals have the surgeon syndrome, and that is that we want to fix it. The thing is that we want to fix it from our perspective--*
>
> *Nurse 1: Yeah, but we're limited. Then again you have to be realistic.*
>
> *Nurse 2: That's right.*

The ED is set up to "process" as many people as possible as rapidly as possible, always with an eye to clearing out space and time for the next patients who may arrive. The normalizing discourse of medicine offers advantages under these conditions because it removes the social, sentient body from consideration and focuses solely on the objectified, insensate body as it moves along the "assembly line" from triage to disposition, permitting the person to show up only in mechanical terms, as perhaps the owner of an automobile brought in for repair. This conception of the patient is taken up in language patterns as well as in practices. For example, nurses spoke of "road testing" patients who had been sleeping off alcohol or recovering from seizures. Such a stance on the part of those who provide care for the body, however, reduces both providers and patients to mere vehicles for the body-processing system.

<u>Medicalizing Control</u>

Under such circumstances, control issues rapidly become predominant in interactions with patients, setting up the caregiving situation as a potentially adversarial one. Problems which are "unfixable" with the relatively limited armamentarium of emergency medicine are reinterpreted as more narrowly-defined problems which could be "fixed" by individual patient actions, such as compliance with recommendations to "stop drinking." Patients who resist compliance, then, are encountered as obstructions to their own care and that of others. Compliance is a proxy for the degree to which patients will agree to collude with providers in medicalizing their problems; that is, in allowing the definitional parameters of their problems, and thereby the assumed causes and solutions of their problems, to be narrowed by medical personnel.

Conrad and Schneider (1992), in their now-classic treatise on the medicalization of deviance, assert that "deviance that is considered willful is designated as crime; when it is considered unwillful, it tends to be designated as illness" (p. 36). Heavy users of ED services, as a group, are "deviant" patients, in that they deviate from practically understood "norms" for patient behavior, both by coming to the ED more frequently than usual and by having problems of questionable legitimacy (Grief & Elliott, 1994; Jeffery, 1979; Kelly & May, 1982). To the degree that these patients resist normalizing medicalization, they become health care "criminals."

> *Physician: It's, you know, it's like a hardened criminal almost. It's the same sort of analogy as a hardened medical case with deep-seated addiction problems and underlying medical problems. Those people are always going to have to be caught by the safety net of the emergency department. They're never going to be able to take care of themselves. Our doors are open for them, and they have to be, because no one else is (chuckles ruefully) going to take them and they're not going to, or not going to try, or be unable to make the efforts to do it themselves.*

Many of these patients' stories, however, belie this common assumption on the part of providers and others that they are not making efforts to take care of themselves. It is, in fact, sometimes these very efforts, carried out too vigilantly, that cause providers to "criminalize" those who will not be "medicalized."

Nurse: I can think of, oh, Mister Nasty, the COPDer [chronic obstructive pulmonary disease] who, uh--you know who I'm talking about, W----? Oh, man, when he rolls in the door, I just--I don't even want to take care of him. He's an older guy, probably, you know, like in his 60s but he looks like he's older than 60. I think he's pretty weathered from this. And I forget--I think he has asthma and COPD maybe? And he is just mean and nasty as a snake. And, uh, he'll come in and he doesn't like--and, on one hand, I can see where he's coming from. He doesn't want an IV. He doesn't want blood gases done on him. Um, he just wants to have his treatment. But he'll like be--go to the point that he doesn't want a chest x-ray, you know? And, uh, I mean, that's totally non-invasive and it would be really helpful diagnostically. I think he does half of it just to be obstinate. The other half, I think, is legitimate of having a lifetime of respiratory problems and getting poked all the time. And he doesn't want to be poked. But he's like the meanest, one of the meanest people I've ever taken care of.

Int: Well, what does he do? I mean, when you say he's mean, like what does he do or what does he say?

Nurse: You know, he'll say, you know, you'll be, 'Okay, let's get undressed'. 'No'. You know, 'Okay, if you don't get undressed...', and then you have a dilemma there because you do have someone who's usually in severe respiratory distress because he'll wait until the last minute. But then he won't, um, he won't even comply with getting undressed. And how are you supposed to do an examination on him if he's not undressed? And our policy is you undress or you don't see the doctor. So then you have the dilemma of well, is he competent enough that you can actually--and every once in a while, he'll get escorted out. And usually we always have to call Security.

Int: Just because he refuses to--

Nurse: And he'll say, like, you know, you're like, 'come on, let's get undressed'. And if you approach him, he'll say, 'don't you fuckin' touch me'.

Int: So he can't be sort of humored along or coaxed or--

Nurse: No, absolutely not.

Int: And so he gets escorted out then because he refuses to get undressed or--

Nurse: Yeah, I mean, what does he want us to do? If he won't even like, you know, allow anyone within 10 feet of him. He just wants the, you know, the neb[nebulizer breathing treatment]. (uh huh) You know, I mean, someone like him maybe he'd benefit from having a neb set up in his place of residence.

> *Int: So that he could do it himself.*
> *Nurse: So he can just do it himself.*

Here the patient insists on maintaining control of the situation by actively resisting participation in customary procedures, even when it means he is "escorted out" and thus deprived of care. Likewise, providers insist on maintaining their form of control over the patient's body by insisting that he comply with "policy" and undress. Both patient and providers lose sight of their mutual aim, the amelioration of the patient's symptoms and restoration of relative healthiness. The struggle for control becomes predominant, becomes an end in itself.

The patient also claims diagnostic authority over his condition, posing a challenge to the authority of the physician to diagnose and prescribe. The element of blame surfaces here in that the patient, while having legitimate respiratory distress, "waits until the last minute" to come to the ED; the underlying message is that the patient has failed in his effort to be his own diagnostician and thus should now allow others to fully take over this task. The patient is also being uncooperative as a learning tool for residents who are eager to perform a full assessment and document their findings (Becker, 1993); by resisting undressing for his exam, he deprives them of the "right" to learn from his body. For the patient, however, this noncooperation may represent a vigorous effort to care for himself properly, as the following narrative from a patient's perspective suggests:

> *Patient with asthma: Yes, I'm an asthmatic, and I have been asthmatic since age four, this is my little girl [his asthma], and I raised her for fifty-two years, and I try to get people to understand, this is, this is my woman, my wife, and my lover, and I know what she needs. And it's very ironic that when I have to come into the hospital, that interns especially, they always want to try something new. They cannot believe that a patient could possibly know what they need to make them better, to get out of their hair. ...Good example is, I was at ___ Hospital about two years ago, and they put me in a room across from a room that had just been painted. So paint fumes got to me, and started an asthmatic attack. So then when*

> *they realized I was into a full blown asthmatic attack, they decided that they would experiment with new drugs. I told them this is not gonna work, what I need is aminophylline IV, and an Isuprel inhaler. 'Oh, we don't use Isuprel inhalers any more.' Fine! Take this money I got in my pocket, go down to the drugstore and get me an Isuprel inhaler so I can knock this out of my system. 'Cause this young lady's been with me fifty-two years. She didn't graduate and leave home at twenty-one like she was supposed to, she decided she was gonna hang in there with her old man. So I've had to take care of her; I know what she needs.' Well, needless to say, they went ahead and tried their little experiments and realized that I was getting worse, and came up with—an Isuprel inhaler! That they just happened to have in the pharmacy. You know, and let it be known that after I was discharged, they gave me three more out of the pharmacy that they did not have. So it really amazes me, you know, that uh, I know less about my asthma than the interns who come outta college, even though I, I haven't been to college, I've just lived with her for fifty-two years.*

The deterioration of the care relationship into one in which control issues are paramount means, for this patient, a threat to his autonomy and ability to care for himself (Becker, Janson-Bjerklie, Benner, Slobin, & Ferketich, 1993). For caregivers, this sets up a situation in which they are treated as antagonists rather than advocates, resulting in feelings of impotence and anger that in many ways mirror those of their patients.

The focus on controlling these patients, dictated by the urgency of time pressures, may actually blind caregivers to the possibilities for more effective interventions with patients before they become "frequent flyers":

> *Nurse: My favorite story is Robert McMichaels. Do you guys remember Robert? Robert McMichaels was a guy who was seen 26 times in 22 days in the month of December. And was actually at one point arrested for the abuse of the 911 system.*
> *Int: Oh, he always called the ambulance?*
> *Nurse: He called the ambulance from a Taco Bell. You know, he'll go somewhere and call the ambulance, finish his taco, and then right when they get there, he sounds or acts really lethargic and like he just had a seizure, and comes*

in, and he was really dependent. He didn't do anything for himself and it was a real burden on us because he wouldn't even bear weight. We always had to transfer him and help him stand, and help him get dressed and undressed. You know, here's this grown man that had just ordered food somewhere and really taking care of himself and when he gets here, he's really dependent. So he was kind of a burden on us. Um, he'd be medically clear. His chief complaint was always something like right foot swelling. And we would look at his foot, x-ray it and say it's fine and give him an ace bandage. And then he would like do something disgusting like pick his scabs off until he was bleeding and then say I can't leave, I'm bleeding, and get his blood all over the ER and really make a scene. So we really had a, always had a hard time discharging him. We would clear him and say, he's medically cleared. PES [psychiatric emergency services] would see him and say, you know, we don't want him in PES. He was always a dispo[disposition] problem. He'd leave. He'd go out to the parking lot, do something like have a seizure or pretend to have a seizure, and then get brought back in. So in 22 days, he had 26 visits. And, um, he finally was seen...for like foot swelling again, because he did have some kind of history of CVA, where he did have some, um, dependent edema in one of his feet.

And, uh, finally, I think, one of the docs said, you know, this guy really needs some help, and got him involved in case management. And they got him placed in a psych ward upstairs. And he ended up having an abscess and he was treated for his abscess. And then he went from psych, medical psych, to some kind of longer term psych place. And then from that--

Int: A living situation kind of thing?

Nurse: No, like somewhere within the hospital. Like he went to somewhere that was like a psych rehab or something. I'm not even sure. But then from there--I'm not sure actually where he went. But then from there, I know he left the hospital and now he's hooked into some kind of a community service. We haven't seen him since November. And he was here 26 times in 22 days. When I heard that, I was so mad because he always had bugs, and he would never eat, and he was just really gravely disabled almost, you know? And we would say, let's give him a shower. So we would get him undressed, get him to the shower and then he'd say he couldn't do his own soap. And then, you know, but this is the same man that walked in to triage. So he would like selectively choose what he could and couldn't do. So he always really burdened the department because he would take

> *several people, and everyone's tension would rise because it was like, I just treated him six hours ago, and it took me two hours to get him out of the department and now he's back. So seeing him was like a real pisser, you know? So finally, when we got--when the case manager got involved, it was like really a good solution. They did a really good job.*

Coming to the ED over and over, as in this patient's case, is clearly a way of trying to obtain some sort of care for oneself, yet the patient shows up in this nurses' story only as burden, impediment, and source of staff tension. There is no sense of meeting the patient as person reflected herein; rather, the patient is encountered as an obstacle to efficient processing of more medically "appropriate" bodies. The nurse's anger arises from frustration with this particular patient's repellent and dependent behavior, but it is also a result of the conflicts that arise in combining the roles of heroic rescuer and everyday "safety net" in a setting where speed and urgency are highly valued. The cultural insistence upon individualism and independence, combined here with the press for efficiency, means that dependency as nonmedicalizable need can only be interpreted as burdensome. Here the patient is criminalized even to the point of arrest before someone finally attends to the underlying meaning of his behavior.

Manipulation versus Desperation

> *Nurse: He was shot and became uh, became paraplegic. So it ruined his entire life. And he had a bad attitude towards that, which I probably would have, too. But he was just a horrible--I mean, he'd throw water pitchers at nurses and he was just awful. And he got very manipulative. I mean, through welfare services, he would end up in foster home after foster home after foster home because his parents could not take care of him, or in nursing homes. He would end up in a nursing home in my home town, which is the heck and gone out in the middle of nowhere, because nobody else would take him. But he would come in here and want to be admitted for--something. God only knows. And nobody would admit him. So he would go out to the waiting room and stab himself in the abdomen.*

> *Int: In the waiting room?*
> *Nurse: In the waiting room. He slit his wrists one day and he stabbed himself in the abdomen one day. I mean, he usually stabbed himself in the abdomen because it didn't hurt. But, I mean, if it penetrated enough, then he'd have to be admitted, or have an exploratory lap[arotomy]. This is the high quality of the ER abusers. But, you know, he would just have no place to go and that's why. And if we wouldn't keep him because he didn't have any place to go, then he'd have to find a reason.*

This story highlights the dilemma of interpretation faced by caregivers: in order to be eligible for care in our medical system, patients must have conditions considered worthy of care technically defined. Simply having no place to go, no one to care for you, and no one to witness your pain is no longer considered a worthy need when need is measured by the prospect of financial reimbursement, as is increasingly the case (see Chapter Ten). This story was not unique; I heard several similar stories at both study sites.

Yet caregivers are personally and professionally confronted with suffering which the "fast food" technical medicine approach of the ED setting is ill-equipped to alleviate. Even though patients have no readily apparent need for technological medical intervention, they do have real needs which cannot be made entirely invisible.

> *Nurse #1: And, I think of every frequent flyer that I can think of, they all either have alcohol problems or they're IVDA-ers [Intravenous drug abusers] and they're in here constantly for abscesses or because they get so drunk. They fall down on a street, they always come by ambulance, and it seems as though, you know, we just patch them up and send them right back out to just do the same thing all over again. 'See you tomorrow!'*
> *Nurse #2: Yeah, it's a revolving door. We don't do any proper rehab, I guess. Proper, you know, give them Valium which is the same as giving them a couple of drinks, and getting them out of our face and then, you know, revolving door, so-called medical care, they'll come back in again. You know, you're not treating the problem, you're treating the symptom.*

Patients and caregivers thus share a certain level of desperation and helplessness: forced to collude in the medicalizing reduction of embodied person to object, of lifeworld problem to individual problem, they move together mechanically in a mutually constructed moral incoherence. For many caregivers, the way out of this uncomfortable feeling lies in naming such patient behavior manipulation and guarding against it even when it is in no one's best interests to do so.

> *Nurse: He came in and he wanted a shower and he was told that it was going to be five hours and he could go to [shelter] and he goes (makes a noise). Didn't like it. He went outside and he came back in, and he had a piece of glass, and he like cut his wrist and said, 'Now, can I be seen?'*
> *Int: Wow.*
> *Nurse: They know how to play the game, a lot of these frequent flyers, too.*

The nurse went on to explain that even then, the patient did not get the shower he wanted; having cut himself, he had procedurally repositioned himself into the category of "danger to himself" and thus was "tied up": restrained in case he tried to hurt himself further. This means that in addition to requiring repair and follow-up care for his self-inflicted wound, the patient now has entered into a standard mental health trajectory in which he must be evaluated by psychiatry for possible suicidal tendencies. From both the practical and the systems standpoints, it would have been far more expedient to simply recognize a legitimate need and allow this man to take a shower, even if this represented a deviation from normal policy, so it is clearly not merely the press for efficiency that is at work in this interaction, but efficiency understood as control. The struggle for control and domination places both nurse and patient in rigid defensive postures that leave no room for retreat or repositioning in the situation. Such a stance leaves nurses feeling misunderstood and "abused" by the patients they are ostensibly there to help.

Some nurses tend to guard themselves against a kind of emotional betrayal by limiting their involvement in various ways so that they will not be "scammed." Nurses and other providers develop and maintain a skepticism and mistrust about these patients, who are viewed as canny "abusers of the system," yet there is also a discomforting awareness that many of these patients may have few other options available to them.

> *Nurse #1: —who can blame them if you can manipulate the...system to your own benefit? You know, if you're out on the street.*
> *Nurse #2: Oh, I think it's kind of sad that you actually have to scam, you know, you know—*
> *Nurse #1: Right.*
> *Nurse #2: —everywhere you go. Everywhere you go, you have to scam.*
> *Nurse #1: Right, it's a constant scam.*
> *Nurse #2: You know, I think that's kind of the sad part about the people who come in—*
> *Nurse #1: Survival just (inaudible)—*
> *Nurse #2: —yeah.*
> *Int: Talk about when you say 'scam', talk about what you're meaning by 'scam.'*
> *Nurse #2: It's a scam. You know full well when people come up to the triage desk that they're just coming in—they'll get dumped off the [alcohol patrol] wagon, you know, from the detox shelters. Uh, or just from the other shelters who, if they say they have a medical complaint, or background or history, that they have to be seen and cleared in order to go back to the shelters or the detox. And so much of the time people with an alcoholic history, as often as not, they won't be shaking, they won't really be in severe withdrawal, but they'll have some nickel and dime complaint. And they just come here—uh, change of scenery, ride across town, um, maybe some food, um, medicine for aches and pains is sort of like secondary. It doesn't feel like it's a primary complaint. I'm not saying everybody does that. But it's such a common theme. And you can see it when people sign in. It's like their complaints wander, they're not consistent, um, and I don't, I don't, I just don't think that—it's a scam.*

There is a kind of double bind at work in the interactions between providers and these patients. When the patients present with their "real" nonmedicalized needs, that is, asking for a shower, a rest or something to eat, they may be considered illegitimate and refused care. However, if they present with a medicalized complaint, they may be suspected of "scamming." For providers, being confronted with patients who do not have clearcut, readily "fixable" medical needs creates a dilemma wherein the moral pull toward responsiveness is countered by the need to control and by the need to protect oneself from vulnerability (See Chapter Seven). The structural constraints of the increasingly narrow settings in which public care is provided mean that providers are co-opted into defending the "system" against the needs of patients, rather than advocating for patients. The true "scam" here lies in the societal pretense of care under the guise of high technology, wherein patients' needs are degraded and interpreted as irrelevant unless they can be "fixed" through technological intervention.

Patients as The Problem

When caregivers are caught up in the effort to control, patients who cannot be readily controlled can only show up as problems, not as complex, unique human beings. Thus such patients can quickly become stigmatized, hated repositories for the range of conflicting emotions caregivers in such a setting try to minimize in order to go on. When this happens, caring can become pathologized (Benner, 1994b):

> *Nurse: We tend to perpetuate the problem because we care for them. We dry them, we warm them, we give them water, we feed them. You know, I mean, it's a double-edged sword.*

One nurse told me, tongue perhaps only partially in cheek, that she had the solution to the problem of frequent visitors to the ED:

> *Nurse: A neon line. And we can just say just follow that neon line to your bag lunch, to the methadone clinic, whatever it is. The real reason they signed in. And then we could just have them, you know, there can just be a pit of alligators at the end of the neon line. (laughs) You know? And then*

> *that's the only way our problems are going to be solved here. Because, you know, with substance abuse there is, there's no solution until that person's ready to quit. I mean, like, you know, some of these stories of people being reformed and showing up later, it's wonderful but those people had to want to quit. Because for as few of those, there are probably five times more who don't want to quit, aren't going to quit, but yet will continue to show up always. And always have major medical problems because of their substance abuse. Unless you're going to lock them up and leave them there, they're not going to get healthy until they want that. And we're never going to lock these people up because it's not an American thing to do.*
> *Int: What do you think makes them decide they want that?*
> *Nurse: I don't know, you know, I mean, for me, if I lost my job, I'm living on the streets, I have lice, I have major medical problems, I have no money, that would be the bottom of the barrel for me. That would be my rock bottom and I think I would have to say, you know, they say you always have to hit rock bottom. But some of these guys don't have a rock bottom, or their rock bottom certainly isn't our rock bottom.*

When the patient is constitutive of the problem, the otherness of the patient shows up only with respect to his/her difference, as wholly other, unrelated to "us" (Benjamin, 1988). This stance permits a false sense of protection from vulnerability in that it covers up our relatedness with the other and the possibility of our being like them. Here the patient is understood as a wholly independent self, engaged in an instrumental relationship with the body in which the body's performance is directly related to the cognitively-determined "right" actions taken by the person and the body's breakdown is attributable to moral weakness or failure. In this view, the patient is assumed to be a radically free agent, able to make behavior choices in a purely intentional way. The patient thus becomes solely responsible for his or her illness, particularly if the illness is related to self-destructive "lifestyle choices" or stigmatized conditions.

Health as Absolute Value

Lowenberg points out that "assigning moral blame to the individual for illness assumes that health is an absolute, ultimate value taking precedence over all other values" (1989, p. 185). Such an assumption actually also underlies many paternalistic interventions. Neither the individual responsibility perspective nor paternalism address the issue of competing goods. The following story related by a nurse reveals that for some patients, other values may take precedence even over health.

> *Nurse #1: Did anyone tell you the choking, uh, the, uh, um, Mr., uh, Mr. M. who was wheelchair-bound and refused to go to [extended care facility], who choked and died in the emergency, in the waiting room?*
> *Int: No, nobody told me that.*
> *Nurse #1: Did anybody tell you that story? Okay. Uh, Mr. M. was a, uh, wheelchair-bound, uh, sort of semi, semi, semi-paraplegic. He basically had sort of—as part of his SSI, uh, had exaggerated his leg injuries so long they put off therapy and physical therapy to the point where he was wheelchair-bound even though he had function in his legs. He, you know, uh, he just sort of let himself deteriorate. Um, uh, to the—and he was collecting, uh, SSI. And, uh, would make the rounds of all the hospitals for, uh, various social needs, uh, frequent admissions for, uh, leg cellulitis and pneumonias. Um, um, and, uh, he had his SSI checks sent directly to the liquor store where he could, uh, uh, so—well, they would cash a check, give him some money, and, uh, and all the alcohol that he needed.*
>
> *Anyway, he ended up staying, coming here and being admitted on five different occasions. And each, each and every time it was almost like a social admit, a failure to thrive kind of a thing. We got him cleaned up, um, uh, and got him admitted, got him a bed in [extended care facility] on five separate occasions. And each and every time it was his day to be discharged from this hospital and transferred to [extended care facility], he refused to sign the papers that would allow [extended care facility] to collect his SSI, and, thus, be paid for his care— on the theory that he wanted*

to go to [extended care facility] to be taken care of, but he still wanted to have his $660 a month in SSI money on top of it.

And we just couldn't do that. So we ended up discharging him. But he never left. He stayed in our waiting room. This went on for a period of over 6 weeks of admission, refusal to sign the papers, and discharge. All the while, he was still sick. He never really got well. He was literally living in our waiting room. He was a fixture in our waiting room. And he would, and, and would beg money and harass the people.

Finally some good-hearted, um, I think it was a patient but it might have been a volunteer, gave Mr. M., uh, one of our, uh, peanut butter sandwich bag lunches.

Nurse #2: Oh, no.

Nurse #1: Someone came to triage and said, I think you should come over to the waiting room. There's someone who's on the floor. We got there. He was on the floor, out of his wheelchair with a half-eaten peanut butter sandwich by his side, cyanotic, pale and gasping for breath. He was rushed to a trauma room, where, where we tried to suction peanut butter out of his trachea.

Nurse # 3: Do you remember this guy? He was huge, like very obese. He'd slide down in the bed and it would take six people to pull him up. And he couldn't breathe.

Nurse #1: Okay. Uh, he subsequently died, I believe, in the trauma room, uh, when intubation failed. So that brings back the first, second and third rule in the emergency room that sooner or later, no good deed goes unpunished.

Nurse #3: [Patient name] (inaudible), I mean, [name], uh--[referring to another "frequent flyer" patient who has just returned to the ED]

Nurse #1: Yeah, he was here yesterday.

Nurse # 3: I just told him I'd give him a sandwich.

Nurse #1: Fair enough.

Nurse # 3: I figured it was cheaper than an ER visit.

Nurse #1: That is why we no longer give out peanut butter sandwiches. They're too hard to suction.

For the patient described in this incredibly difficult situation, the fear of losing control over his finances, of being forcibly deprived of the alcohol on which he has become dependent, and of being confined in an institution was greater than the fear of illness and the desire for help and "health." Essentially, the medical care system in this case offered Mr. M. a choice between being medically cared for and almost everything else in his life--his money, his (relative) autonomy, and his addiction to alcohol. Seeing his resistance to assigning his money to an institution as a choice between "healthiness" and "unhealthiness" leaves out the way "health" depends on factors other than the mere intactness or mechanical function of the body, such as one's embodied habits, practices, and constitutive relationships with others.

Unfortunately, the intensifying economic constraints of our system of health care mean that those who are poor, like Mr. M., face such choices regularly; reliance on emergency care is their version of a reasonable compromise. It can be difficult, in our culture, to imagine a different way such a situation could be handled, or, better yet, a way such a situation could be prevented. Because we culturally vacillate between the totalizing and mutually exclusionary perspectives of paternalism and individual responsibility, it is difficult to imagine that there might be room for a reasonable, even practical compromise. Providing alcohol for Mr. M. in the long-term care situation, for example, might have ultimately proven less expensive in time, money, and human terms than the alternative. But to do so would challenge our cultural constructions of blameworthiness and social control. Underlying the resistance to such a compromise solution is the subtle but significant influence of behaviorism on a culture in which the expectation of economic productivity is near-universal.

A physician shared a similar story of a patient who was uncooperative with plans for her care in an extended care facility.

> *Physician: She was a lady who become a big deal one day because, um, she's a lady who, um, she's probably alcoholic, um, who's homeless also. She spends a lot of time in and out of the emergency department. She's also paraplegic. Um, she came in here, was admitted one week for, uh, basically for placement...*
>
> *She'd been in here several times with the same kind of issues, pneumonias and such, and--brought on by her lifestyle. And she'd been in the hospital finally to be placed [in an extended care facility] and then she chose to leave AMA [against medical advice]. She didn't want to get placed. This wasn't what she wanted. And so two days later she comes into the Emergency Department with a body temperature of 27 degrees. And it was remarkable from two perspectives was that, uh, she [had] probably the lowest temperature I've ever seen on somebody, and --. And Dr. H. coded her for three hours, asystolic arrest. And after getting her body temperature up with bilateral chest tubes, got her cardiac rhythm back in hour or two. And she came back to normal neurologic status.*
>
> *And I come on at three o'clock and the reporters are out there wanting to know, 'Well, Doctor, is this another homeless person of the city, you know, a failure of the system to,' you know, of us for not making the, uh, these poor people a place to live. And I tried to carefully explain to them that, 'No, Miss ___ had a very difficult exposure, uh, probably related to her alcoholism. And, unfortunately, she recently had been admitted for the very purpose of being placed in a nursing home which she had willfully chosen to leave.' And all that got edited out of the six o'clock news 'cause that wasn't the perspective that they wanted to show. And so now Miss ___ is still alive, uh, despite her room temperature body temperature, she, uh, did just fine. She managed to survive that.*

Here the patient's refusal to cooperate with admission to the nursing home is interpreted as the proximate cause of her subsequent admission for hypothermia. There is anger and frustration in this physician's story, but it arises not only out of the patient's intractable behavior, but also from the way such "difficult" patients make caregivers show up as less caring, less effective, and less authoritative (Plough, 1981).

This story also points to the interesting taken-for-granted aspects of "lifestyle" as a cultural construct. As "lifestyle" comes to be viewed as distinct from one's "life," we foster a view of persons in which each resides within a kind of individual "biosphere," the controls of which are at our command. "Lifestyle" itself becomes the preventive for disease, its causative agent, and its cure. Such a view is not incompatible with both the mechanistic aspects of the biomedical approach and the individualism of the market approach. But to the degree to which we take up this view, we lose sight of the way in which our ability to even imagine individual possibilities for change is shaped by our situatedness in a world that is already meaningful for us, our taken-for-granted understanding of how the world "works." We lose sight of the ways care and concern from others can open up our possibilities for change.

The Control Stance

The control stance dictates that the way to change behavior is through force, either the internal force of the will (individual responsibility) or, if patients fail to change in the prescribed ways, through the external force of "locking them up" (paternalism). When neither option is available, or when the failure to change results in the patient's death, caregivers experience feelings of painful ambivalence. A nurse tells about the death of another "frequent flyer":

> *Nurse: Out on the bench in front of the hospital. One night Security came up. They said, 'Oh, we found him ["frequent flyer" patient] on the ground'. I said, 'What do you mean? What did you do with him?' And they [said], 'Oh, we put him back in his chair'. And I said, 'Oh, okay'. We didn't think too much about it. And that night we're in triage in the middle of the night; like a couple of hours later I go, something's weird about that story. And then they said they picked him up again and this time they put him on the bench. And I said--'He was okay and he was breathing?' and they said, 'Oh, yeah, he was fine.' So I looked at [second nurse]. I said, 'Something's really not right.' And I go out there and he's dead. He's stiff*

> *as a board; he's on the bench. And I looked at her and I said, 'He's really stiff and he's really cold. And you're not dead until you're warm and dead.' So I looked at her and I go, 'Shit. We have to take him in.' So we did. We wheeled him in [Room 1] and put him on the monitor. He was asystolic. And I felt so bad because I didn't like the man very much. But I remember feeling really like, oh, God, thank God, he's finally dead. And then that other part of me was like, don't say that, you know? So torn between like being glad and not liking the man to feeling guilty about being glad.*
>
> *Int: What was he like? I mean, what was--did he used to come with?*
>
> *Nurse: Alcohol. He had no legs. They had both been amputated. And he was just always filthy and drunk and not very thankful and very demanding. Every time you saw him you just thought, oh, not you again. We'd have to shower him and get rid of the bugs and cover his feces and... And we kept thinking, God, when is he going to die? Would the man please just die? And then when he did die, we're like, oh God, now he's dead. You know? You can't win.*

This excruciatingly honest story contains a subtext wherein blame and shame are shared by both the patient and the nurses. The patient is blameful because he is ungrateful and demanding and noncompliant with instructions, and perhaps also because he allowed himself to become such a terribly unfixable person. The nurse is blameful because she had secretly wished for his death and because she did not follow up immediately when first told about the situation. But there is a deeper shame, unarticulated but revealed in the nurse's mixture of emotions, that arises from the moral failure to truly see this patient as a sufferer, as a fellow human being, as something other than an impediment to the work of body-processing.

Withdrawal of Care

The need to control also stimulates a type of moral discourse in which discussion of "rights" prevails, including the "right" not to care, as the following discussion shows:

> *Nurse: Well, they say they're going to pay the bill themselves. But, you know, you can't squeeze blood out of a turnip, so it doesn't really matter--if they don't have the money, they're not going to pay the bill. But what our doctors can do, and hopefully you'll see more of that down the road, is our doctors have the right to do a simple screening exam. You walk into the room, you say, I see your finger is infected. How long has it been infected? It's been infected a couple of days. Um, okay. Um, my recommendation is to go see your regular doctor. We have the right to do that. You write them up, you make a chart, the doc doesn't evaluate farther. You open your mouth and you say, you've got tonsillitis. My recommendation is that you go see your doctor because you need antibiotics. Our doctors aren't very willing to do that. I think a little bit, some of them, some of the time. But as long as the patient is here, let's do see them. And you're right because--*
>
> *Int: --write up a chart anyway. Kind of, uh--*
>
> *Nurse: You know, what needs to take place is the educational process has to be enforced.*
>
> *Int: As far as them--*
>
> *Nurse: Yeah. You came into the emergency room, we saw you, but we didn't take care of you.*

The increasing enrollment of Medicaid patients into managed care plans provides economic justification for the withdrawal of care, in this case from patients who actually do have readily "fixable" conditions. Here the choice to do so, however, is framed not in economic terms, but in punitive terms shrouded in rights language. The patient, as responsible for his or her illness, is also made responsible for fixing it. Patient education becomes a matter of "enforcement" of economic policies, rather than an issue of patient welfare. The discourse of personal responsibility carries just this danger, as Lowenberg warned prophetically several years ago in her analysis of the "holistic health" movement:

> Beyond the economic realm...withdrawal of support is beginning to appear in other institutional settings. For instance, health care workers could increasingly feel that efforts in behalf of patients they see as inflicting illness

> on themselves, thus "choosing their illness," do not merit the same attempts in their behalf (1989, p. 161).

Catherine, a chronic alcoholic with other major medical problems, confronted this trend when she arrived at the ED one night. The following excerpt is from fieldnotes.

Wanting to Be Seen: Catherine

> Catherine is a patient about whom almost everyone at the hospital told me as soon as I mentioned an interest in "frequent visitors." I see her for the first time when she arrives by taxicab one morning at 3:30 a.m., obviously intoxicated. The triage nurse, alerting me she is there, tells me she told Catherine that if she didn't have anything wrong with her then she could go to [the alcohol detoxification unit], and Catherine then started to complain of a leg problem. The nurse suggests that I go out and talk with her now in the lobby.
>
> Catherine, a skinny little woman sitting in a wheelchair, is tearful and talking loudly, speech slurred from alcohol. After I explain my study and ask to talk to her, she begins to tell me about her family, crying intermittently. After only a few minutes, a security guard signals urgently to me that she wants to talk to me. I stop the interview and go out. "She's always like this," says the guard. "She comes in all the time and she's always like this." I am somewhat irritated by the interruption. "I know, that's why I want to talk to her; I'm doing an interview, I'm doing some research," I reply. The message seems to be that I should not take the patient seriously, or that efforts to care for or help her are futile.
>
> Periodically during the interview Catherine grabs her abdomen and bends over from the waist as though in sudden pain. Her appearance makes me speculate she may have some pancreatitis. She cries and blows her nose frequently. She rolls her head backward expressively and clenches her fists

dramatically. Catherine's clothes seem too big for her. She has a rather nice-looking leather jacket and it is clear she was once a very attractive woman. Her raw emotion is like an open wound.

After we talk for a little while, she complains that her leg is getting numb and she can't walk on it; at her request I wheel her back over to the registration clerk's desk. Her paperwork has not been started; the clerk says the nurse needs to see her first, even though the nurse already saw her once when she first arrived.

I leave the patient with the clerk and go back into the department. I tell the nurse that the clerk said she needed to be seen by the nurse. The nurse goes out and I hear her saying loudly as though the patient were hard of hearing: "So you want to be seen by the doctor?" Catherine apparently replies affirmatively, because the nurse comes back into the department shrugging her shoulders and apologizes to the other nurses for not being able to dissuade her from registering.

The nurse brings Catherine into a treatment room. When the nurse returns, I ask how it went. "Oh, fine, she just wants to be seen by the doctor, so we'll see her," says the nurse. The doctor goes to see Catherine, stays less than five minutes, comes out, and writes discharge instructions. Another nurse then goes to get Catherine to sign her discharge sheet but comes back out reporting that she complained of numbness in her leg and when he checked for pain (by needle test) she didn't move in response. The doctor replies flatly that the nurse should tell Catherine that she can either get dressed and go home or go to detox. Another nurse asks if Catherine might have peripheral neuropathy from alcohol. The doctor replies gruffly: "She probably has everything. You tell her she can get dressed and leave or

> she can go to detox." He swivels around in his chair. "Don't do any more pain stuff," he adds.
>
> The nurse goes back in, comes back out. I ask what the response was. "She's getting dressed; she doesn't want to go to detox," the nurse answers.
>
> The patient is demanding that the hospital pay for a taxicab. The nurse insists that the patient can call her family to come and get her, reminding her that the alternative is detox. When I leave the department the patient is in the lobby "making a fuss," according to one nurse, but using the telephone to call for a ride [Fieldnotes].

Catherine, I later learned, came to the ED more than 20 times in one year. She had acquired an almost legendary reputation among providers, who talked wonderingly of the amounts of alcohol she could have in her bloodstream and still walk straight in high heels; she was rumored to have been beautiful in her younger days, to have been a prostitute, to have been funny and intelligent and even pleasant in earlier years. Now she seemed to have exhausted the goodwill of caregivers, who viewed her as an intolerable burden they were loath to accept. and who used the threat of "detox" to control her. Catherine persisted in "wanting to be seen" as fully human, but the stance of control allows her to show up only as a problem that cannot be fixed.

> *Nurse: I think for a lot of these people, it's that they know you have to see them. They know that. And they don't want to have to wait and go to a doctor's office. They know they can go to the ER and get seen and they don't have to take responsibility. And also it's in and out and they don't get to know you so well as in a doctor's office. I mean, they get away with stuff they'd never get away with at a doctor's office.*
> *Me: Like what?*

> *Nurse: Just being rude. Like, 'You have to see me. Are you refusing to see me?' And I'm like, 'No, I'm just giving you some options.'*
> *Me: So you think the main reason they come is for medical care?*
> *Nurse: Yes, that and just not wanting to make a decision for themselves. It's like, 'Well, I'll just go to the ER.'*

This excerpt illustrates the double-bind situation in which patients find themselves. The patients' careseeking is here understood as a power tactic, an effort to "get away with" something at the providers' (or the "system's") expense. Yet they are simultaneously characterized as morally weak, "not wanting to make a decision for themselves." Such an apparently paradoxical understanding of "frequent flyers" points to the social control functions of the ED setting and of medicine itself as an instrument of social control (Zola, 1994).

The Market Model: Medical Darwinism

Although it was not the norm among most providers I spoke with, I found several who espoused a kind of medical Darwinism regarding health care for these patients, arguing that, as one nurse put it, "people don't have a right to medical care. You have a right to what you can pay for. I know a lot of people don't agree, but that's what I think" [Fieldnotes]. A security policeman echoed this sentiment, furthering it by saying that if people don't take responsibility for their own health, then society has no obligation to continue to try to help them. Cynical about the possibilities for change, he believes people "make choices" and that many of the patients who are frequent visitors didn't "make choices for survival" as he did.

The personal responsibility and market perspectives here dovetail neatly, but they leave little room for recognition of our common humanity and vulnerability. As economic pressures both within and outside the health care setting increase, and as "outcomes" narrowly defined both temporally and physiologically become the sole measure of value, the meanings of "care" and "healing" are at risk of being lost. A practice based primarily on personal responsibility and cost consciousness can also convey unintended meanings, as suggested by this discussion between two nurses who described how the "routine" altered-level-of-consciousness medical work-up might not be immediately initiated on patients who were frequently seen with such symptoms secondary to alcohol:

> *Nurse #1: Well, we're getting cost conscious, and we know that this is a waste of all those resources. We could be giving it to people who, you know.*
> *Nurse #2: So we defer care. If they don't wake up, then we go ahead and do the million dollar work up. But if they do start getting lighter, you know-- you know, and obviously waking up, then we just go ahead about the business. And even at the end of it, very often, you know, give them a bag lunch. [But] sometimes maybe what we're communicating to them is that you're beyond help; we can't help you; we don't care about you, and that sort of thing. And I hadn't thought about that until now. And then that's something that like--if you do that and they come back over and over it's like, this is the last stronghold (inaudible) where they might get care. And we're communicating that we don't care about you anymore. We're not doing all these things for you that we used to do for you. So, in a way, maybe we're perpetuating the cycle of maybe violence in that way because the response is that you don't care about me and this is my last place.*
> *Nurse #3: But, on the other hand, it is a cost effective mentality.*
> *Nurse #2: Oh, yeah! It is now and we have to adhere to that more and more and more.*

This insight shows recognition that all activity is meaningful and interpreted, that medical interventions are not merely neutral technical procedures. This nurse also links patient violence with the patient's desperation at not feeling cared about (See Chapter Seven). The option of withholding the usual procedures from patients who are judged culpable in their illness carries an implicit message of abandonment for some patients. However, as several nurses pointed out, the medicalization of patients who have primarily social needs may expose them to unnecessary risks as they serve as "teaching fodder" for residents.

The "Undergrounding" of Care

An alternative option is for care to go underground, as this excerpt from fieldnotes shows:

> The ED is on critical care divert this Sunday night and it is pretty quiet in all the areas. I spend most of the evening talking with the triage nurses and watching them check people in. The gurney garage is empty and there are only three people in the medical ward. The trauma side is pretty quiet too. One of the triage nurses says that there was somebody in the gurney garage earlier who might have been a frequent flyer, but no one came out to get him to take him back and he apparently finally left on his own. "No one comes out and gets him because there's nothing we're gonna be able to do for him, and if we fill up the slots with people we can't do anything for, then we won't have room for the people we *can* do something for," she observes [Fieldnotes].

In this instance, not bringing the patient back could be interpreted as withdrawing or refusing care. However, for exhausted, homeless patients whose "real" need is for a safe place to rest for a few hours, such lack of action may actually exemplify a caring responsiveness, in that the patient is not forced to undergo medicalization. Here care goes "underground": the patient is registered and the paperwork put through as usual, but the patient's body is not made to undergo processing as an object. Instead, providers quietly agree not to notice the patient and the patient agrees not to get upset over not being called back. In this alternative version of collusion, patient and provider enter into an agreement to bypass the "system," a potentially risky move for the nurse, but one which allows the patient to show up as human and in need of basic care. Such an option sidesteps the control scenario, but may leave both patient and nurse dissatisfied and anxious over their unspoken challenge to the "system." Low-tech care such as rest and food is rendered illegitimate, even vaguely subversive.

Beyond the ED

Naming the Larger Problems

The emergency department as safety net was at one time extended and supported by other services which now seem less available (See Chapter Nine). Thus providers are confronted with problems beyond the reasonable capability of the ED's resources.

> *Nurse: You know, it's such a social issue. It's so much more of a social issue than, you know, than actual medical problems in half of these people. But-- I think that the thing about it is that they do have medical problems as well, you know, unfortunately. And, uh, I don't know. You know, I was thinking the other day about, yeah, these people that just come up to triage and sign in for-- ridiculous things. And you know that they're just pulling something out of the hat so they can give you a complaint. And it's just really frustrating that we have to, you know, triage these patients and have them seen and worked up. And you know, if they get a medical workup, there's going to be something that they'll find, you know. So, I don't know, I mean--*
> *Int: And so there, you mean you think there's a group of these patients that come without any, um, real, anything wrong with them.*
> *Nurse: Yes, I definitely, without a doubt.*
> *Int: Why do you think they're doing that?*
> *Nurse: Why? Because, um, uh, first of all, a place to hang out. A warm place to sleep. Um, if they're lucky enough, to sign in on a busy night and, you know, their name won't be called for [a few] hours, hey! You know, [a few] hours in the waiting room. Um (pause), and I don't know; I'm not really sure. I don't know if people think... oh, the hospital, it's where they'll take care of me. I guess! I mean, I don't know. Maybe if I was in that situation, I would feel as though, you know, it's a safe place. They're going to take care of me.*

> *Int: And from, like from a nursing perspective, what's the problem with that?*
>
> *Nurse: The problem with that is, um, that we just do not have the resources to be--we can take care of them. We can take care of their medical problems. We can't take care of all the rest of it, unfortunately. And that was the really frustrating thing for me when I first started working here. Um, you sort of want to get them all put back together and, you know, send them off to a place and the fact of the matter is that, you know, we, we can treat their medical problems but we put them back out on the street and they're, you know, we don't help their social situation. But, uh, I don't know what the answer to that is. More social service or something. I don't know because it's such a big issue. And I think a lot of the people--I know working out at triage, half of the people don't even sign in. They just come and sign in to talk to the social worker. So which, I mean, that's okay, I guess, but it just seems like there's got to be another way. (pause) I don't know. I don't know if there's just not enough resources in the community, or people just don't know [about them]. I think there are more resources out there than people are really aware of. But I think [it's] definitely a big social issue.*

Here the problem of "frequent flyers" is understood to be not merely an individual problem, but a structural and social one that is experienced as overwhelming. Our society asks providers in "safety net" situations such as the ED to "fix" problems created or made worse by the system of which they are a part. This nurse struggles to gain enough distance to name the problem, but the connections between the acute care medical setting and the larger community are not easily made, even by those within the "system." The arcane complexities of our snarled system of public and private social programs mean that ED care providers often practice as though inside a bell jar, unable to avoid seeing the horrors of the world outside, but unable to reach it with helping hands.

Discussion

The great danger in calling attention to the way the control paradigm plays out in practice in a setting such as the ED is that it is all too easy to slide into a mirroring discourse of opposition, in which the patient-as-problem interpretation is turned on its head and the providers become the problem through their insensitivity and negligence. There is nothing new about finding that providers make moral judgments about their patients, as the literature in this area makes clear. Yet, as Jessica Benjamin has written, "to reduce domination to a simple relation of doer and done-to is to substitute moral outrage for analysis" (1988, p. 9). Beneath the adversarial posturing of both providers and patients rests a shared human fallibility, a vulnerability to the unexpected and a hidden conversation about notions of what constitutes a good life, a good death, and a good society (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1991).

We cannot reach an understanding of that vulnerability through biomedicine, but simply because it cannot solve this problem for us does not mean that biomedicine created it. As Gordon (1988) observed,

> to continue to blame biomedicine exclusively for its ills is to reproduce its own ideology--that it is independent of society and has an exclusive relationship with nature. Biomedicine's practices take place against a particular background of what it means to be human...sickness expounds a truth about the order of the world as much as the body of the sick person (p. 42).

The stories in this chapter reveal how the desperate need for low-technology care is interpreted as illegitimate within a setting and a system biased toward high-technology intervention and control. Those whose conditions are chronic or not readily remediable are often experienced as intentionally obstructing the care of those with more "legitimate" conditions. The medicalization of basic needs into medical symptoms is a way in which both clinicians and patients collude in covering up the failures of the "system." To the degree to which the needs of heavy users of ED services cannot or will not be medicalized, the patients themselves are criminalized. As economic pressures on clinicians intensify, they take up roles as "enforcers" and risk losing sight of the primary aim of caring for patients. Control, as we have seen, becomes paramount.

The effort to control and dominate everything--one another, our world, and our own bodies--is a project doomed to fail, despite our best-intentioned efforts and no matter what perspective we assume. This chapter points to some of the moral and clinical limitations of such a position. When we question the legitimacy of our patients, our own legitimacy as caregivers is called into question, but perhaps the greater concern is how caring itself can come to look illegitimate in a system controlled by the need to control.

CHAPTER SEVEN

HELPLESSNESS AND HEROISM

Jack: My friend died under the steps back there. You know, he wouldn't come. I drug [dragged] him! He died. He hemorrhaged. He couldn't stop the bleeding. And he--whoo, that was one. What am I gonna do? Not call 'em? If I don't call 'em, I'm a schmuck for act--you know, I--and when I brought him, they just left him on that thing out in the hall. He was dead anyway, he was a walkin' zombie like me, only younger--he was younger. Some people can handle it. Some of the nurses can't handle it, is what it is. They're afraid. Some of 'em are human, but they're special. Maybe they're a little better...some can take it, some can't. I used to be afraid to cry....and now it don't bother me at all.

Nurse: We used to bet on Nicky's blood alcohol. And he was laid out in the hall one evening just--blotto. He was so comatose, you just sat there and, you know, watched him; there wasn't much that could be done for him. And uh, we were betting on his blood alcohol, as we do sometimes, you know, a quarter and you choose a number and so on and so forth. And you know, here's Nicky, on a stretcher right outside our break room, and you, you think that he's totally comatose. Obviously hears what we're doing and says, 'put me down for 535,' you know. (laughs). And I'll be damned if his blood alcohol didn't come back 535! We died. It was like, 'Oh, my God, now he gets our money!' You know, this man won the bet! He's going to walk out of here with our money, you know. But by the same token, even though you, you, you truly had come to despise these people, it's always still really sad when they die. Because you think, you know, wonder what it would have taken to turn this guy around.

Introduction

The emergency department occupies a peculiar cultural niche. It is at once bastion of defense against finitude and vulnerability and the place where these are revealed most graphically. This chapter continues the close examination of the context within which heavy users of ED services become viewed as problematic by focusing on this aspect of the relationships between providers and patients and between both and the cultural understandings of risk, rescue, and the rescue-able. These understandings, in turn, shape both our responses to one another and the system within which we encounter one another.

Risk and Rescue

The Heroic Battle Against Death

The emergency department, the physical setting in which heavy ED user patients and emergency medical care providers meet, is the site where many of our cultural understandings of risk and rescue are worked out. There is perhaps no other community institution so intensely focused on the task of heroically helping. In using the term "heroic," I mean to suggest an attitude of courage and daring that characterizes the way emergency care providers dash into the very jaws of death to snatch back a fellow human being, just in time.

Death, in the emergency setting, is almost always considered in some sense a tragic accident, regardless of whether it actually is caused by a cardiac dysrhythmia, a car crash, or some other catastrophic, unanticipated event. This contrasts, for example, with the microinstitutional view of death in, say, a long term care unit or a hospice unit as welcomed relief from pain, the anticipated closure of a meaningful life, or as the transition to another way of being or an afterlife. This is not to suggest that people do not come into the ED and die there quite predictably of the cancer from which they had suffered for months or years, but this is not the kind of event for the sake of which such a place exists. It is the sudden and unforeseen that has primacy in this setting. The ED thus represents a kind of cultural zone of protection, the center of our collective line of defense against the terrifying arbitrariness with which misfortune is distributed among us.

Yet through the carrying out of this very mission, the ED also creates a zone in which helplessness is brought to the forefront of attention, because it is the place where our ability to control and predict breaks down before the finitude and the contingency that characterizes every aspect of our lives. Rescue is not always possible, and thus the stance of omnipotent rescuer is ultimately untenable. As Hauerwas (1986) has pointed out, medicine

> tries to justify its power by being what it cannot be--a science that frees us from, rather than teaches us, the limits of our bodies (p. 51).

Vulnerability as Context

But it is not only the realization that rescue cannot always be successful that precipitates feelings of helplessness. It is also the horrifying notion that the rescuers themselves could just as easily be those in need of rescue. A story from my own experience may help readers grasp what this means in practice.

A Personal Story

Many years ago, before the advent of trauma systems, I worked as an emergency nurse in an inner city hospital that received many "knife and gun club" patients (as they were known in the parlance of ED bravado): patients with injuries from shootings or stabbings. One night, I was working when a shooting victim arrived. Within minutes, the ED physician had "opened the chest"; that is, sliced through the skin of the chest, pried the ribs apart, and visualized the heart to try to find the injury before the man bled to death.

Assisting, I stood with my gloved hands inside the man's bloody chest, gently massaging the heart in the attempt to maintain circulation, while the doctor prepared to defibrillate and several other nurses and technicians intubated the patient, started intravenous lines, gave medications, and prepared equipment for use. Less than twenty minutes later, we stopped: the man's injuries were too massive, the body unresponsive to all we had done. The doctor left to speak with the man's family. The other nurses and technicians moved on to care for other, living patients. I was left alone to prepare the room and the body, to re-supply the area for the next injured person's care. I worked quickly, because while we had all been engaged in the rescue attempt, other patients had been arriving in need of care.

My eyes fell on the man's feet. Although his clothes had been violently stripped and cut away from his trunk in the resuscitation effort, his soft white socks remained on his feet where he had pulled them on when he dressed himself hours ago, at the ordinary beginning of his last day of life. One of them had a small hole in the toe. I felt a sudden lightheadedness, a tingling up the back of my neck, a rising lump of nausea. This was a person: he had a life, he had pulled his socks on today as I had, never dreaming that he was doing this for the last time.

There was something profoundly shocking about having just had my hands inside the torn-open chest of a human being who still had his socks on. It suddenly felt like a kind of violation, like rape, confusing and terrible, even though I knew I had been trying to save him. Those soft socks spoke of the profoundly disturbing ordinariness of a life which had suddenly been stopped.

Here, in the very heart of our collective bastion against the unpredictable and the unexpected, I had found myself face to face with the way those I rescued were *like me:* I was, as they were, vulnerable to being irretrievably broken, and we were incredibly ordinary. In perhaps no other setting in the hospital are health care providers confronted so frequently and violently with their own finitude and fragility. On the wards, patients are undressed and gowned; the human identity that attaches to clothing and personal items is packed away in labeled bags. In surgery, the patient's body is almost completely veiled from view except for the scrubbed, shaved operative area. But in the ED setting, people arrive with awful injuries and illnesses, snatched straight out of their everyday lives, their socks still on.

Providers and patients thus meet one another within a context characterized by urgency and vigilance, in which unpredictable dangers obtrude. Death sits always in the back room of the ED, waiting, watching for a weak spot, a mistake, the opening in our carefully constructed universe through which it can grasp us.

The Climate of Violence

Feeling physically safe is a necessary prerequisite to trust. The climate of violence in which we all now live, and which heavily impacts the practice of emergency providers, is a threat to our most basic abilities to trust and care for one another.

Violence "Outside".

For the many poor patients who were heavy users of ED services, the threat of physical injury from others was an ever-present part of daily life. I heard many stories of violence or near violence and the strategies used to avoid or minimize risk. For some, such risks seemed an inescapable part of life:

> *Matthew: That's how I got this [lacerated] lip. I shared a bottle of white port with this guy...and I told him, 'Well, I got a, I got a Susan B. Anthony [dollar coin] left, let's go get another drink,' and he said, 'No, I want it.' So he pulls a knife out on me. Only way he coulda cut me would have been in the neck. Because I had, I was well insulated and he only had a small knife. But then he just busted me in the lip. I said, 'Man, if you want this Susan B. Anthony so bad, here, take it!' I was bleedin' all over the place....And I've been robbed so many times, too, I've stopped counting. The most money I ever got robbed for is about 85 dollars. And this was after I'm buyin' everybody a drink.*

"Frequent flyer" patients not uncommonly present with injuries from incidents like this, which providers tend to attribute to bad judgment secondary to drinking. The societal problem of violence is thus reinterpreted as an individual behavior problem: if the patient had not been drinking on the street, (s)he would not have been a victim of violence. The social context within which violence has become epidemic is unexamined. It is a short step from alcohol being viewed as interfering with a patient's ability to protect him/herself to violence being attributed to alcoholism.

This search for moral explanations for injuries may be viewed as self-protective for providers, in that they can on some level presume themselves immune to such injuries because they do not, for example, have an alcohol problem. But why are "frequent flyers" singled out so specifically for this kind of moral censure? I will take up this question again later in this chapter, but I want to introduce it now.

Patients who come in with injuries from car accidents who are found not to have been wearing their seat belts may be reproved and their injuries made an object lesson for others. But providers do not have the same kinds of stories about such patients as they do about "frequent flyers," they are not considered illegitimate patients, and providers are not so angry about such patients. I would suggest that part of the difference lies in the ultimately--and chronically-- "unfixable" aspect of "frequent flyers."

Henry.

Another "incurable recyclable" who has met with violence in his everyday life is Henry, a 70-year-old homeless man who used to write for television and now sleeps under the eaves of a local church:

> *Henry: My problem is, lady--may I be succinct with you? My problem is, at seventy, I'm fighting cold. I'm always cold! I don't know why; I never had that before. Now, I'll tell you what happened: When I took my radiation for cancer treatments, it destroyed, uh--may I be frank?*
> *Int: Mhm[assent].*
> *Henry: It destroyed my bowel. And I have no control over my bowel. I haven't since. I took those treatments five or six years ago.*
> *Int: The-that was where your cancer was, was, bowel cancer?*
> *Henry: Oh, yeah. Cancer. And I'm having no problem as far as the prostate goes. I'm having no trouble urinating. But the bowel! and they warned me, when you take these treatments, it will affect your bowels. I wouldn't have gone through it had I known, what the, what it was, what was pending.*

Henry is physically unable to spend hours daily waiting in lines at the places that serve free meals to the poor. His bowel condition means that he must always be looking for the nearest bush or bathroom and he must often wear soiled clothing, as he is when he talks with me. Like several other patients in my study, Henry drinks to ease his chronic pain, a self-medication that may exacerbate his preexisting bowel problems:

> *Henry: I came here a couple of times before, way back. Now my problem is, when I get so sick, it's uh, just since the radiation treatments, I go down and buy a few beers, and that relieves my stomach. Uh, just a little bit, but, it's only, uh, for a short duration.*
> *Int: Uh-huh.*
> *Henry: And it, it doesn't cure anything. In fact, when I wake up in the morning, I feel awful. Now, here's what I want to tell you: I never told anyone, I don't--I go to AA, and I talked to a couple of doctors, who are friends of mine, in AA, but they talk about alcohol, but uh...at about four in the morning, 'til about six, I go through the worst stomach pain, and the worst feeling that you can--possibly imagine. That's why I go down and buy a couple of beers, to relieve that.... Um, I need help, lady. I need help. And I need some clothes, my clothes are, I sleep on concrete; look at my pants. [Mm]. I'm ashamed to sit in your presence (emotionally intense, as though about to cry). Damn!*

The emergency department, for Henry, is a place to come for "help" broadly defined, not merely a place to seek "medical" care. In Henry's case, this might include a sandwich or some juice, a safe place to rest for a little while, some dry clothes, a blanket. For others "help" means something more fuzzy: a kind touch, a word, a bit of coaching or coaxing--something very like what "healing" was once, before the dominance of technology. This cry for global "help" was repeated by many of the patients with whom I spoke and recurs throughout this report. "Help" in this sense suggests deliverance from suffering, a comforting presence, an acknowledgment of one's vulnerability (see Chapter Eight), and, as will be illustrated in Chapter Nine, an affirmation that there remain some sources of public goodwill toward the less fortunate. But these patients confront providers over and over with the limits of their capacities for "fixing" what is wrong.

> *Henry: Ooh, since la--my legs have been hurting me for over a year. Ah, you see, uh, I'm telling you a lot of stuff, and I shouldn't. But some... guys beat me up one night and robbed me. And they hit me over the legs with an iron pipe. That was a year ago. [Mm]. 'N' my legs have hurt me ever since. It's in the muscle. [Hmm.] I've read medi-medical journals, tryin' to find out, you know, the source of this thing. It's in the muscles. It isn't in the bones. [Hm.] Because I went over 'n' had Xrays made [Mhm.] ..nothin' broken. And uh, I went to ____ Hospital, I know of a doctor works there, he said there's nothin broken. Nothing. And that's it.*

Pain that can't be diagnostically located in a structural way here goes untreated because it cannot be described in terms of biomedicine's understanding of the body, but it does not go away simply because it is unexplained. Several of the patients in this study suffered from intractable pain in the absence of clear pain-producing pathology. Henry uses alcohol in what he conceives, on some level, to be a therapeutic way. Alcohol's contribution to his vulnerability to physical injury and predatory violence must be weighed beside its mitigative contribution to relief of suffering.

It is remarkable that patients like Henry (and others in my study with chronic pain and alcohol use) were not prescribed pain-relieving medication. While providers may be understandably leery about prescribing narcotic medications to patients who drink regularly, fearing potentiation effects and possible injury, the resistance to medicating such patients for pain may inadvertently contribute to the development of alcohol dependency. Sam, whose story concludes this chapter, is another patient I interviewed who self-medicates with alcohol, at least partially in order to relieve his pain. This failure to treat pain suggests that the negative moral evaluations of such patients cloud providers' ability to recognize when an underlying, untreated or undertreated problem such as pain is contributing to the overt problem of alcohol abuse and associated injuries. But we have still not fully accounted for why ED providers view such patients so negatively.

Violence in the ED.

Though the ED is still viewed as a safe haven of sorts, the violence that permeates the world outside has also infiltrated there, further shaking the illusion of protection the setting is set up to offer. For emergency care providers, the threat of physical violence is now experienced as a part of everyday practice. The shooting death of an emergency nurse in April, 1990 and the increasing concern about assaults on caregivers (Eddinger, 1991; Lenehan, 1991; Mahoney, 1991) prompted the California Emergency Nurses Association to cosponsor legislation requiring education on violence prevention for ED staff (Keep & Glibert, 1992a, 1992b). ED nurses clearly feel physically threatened in their work setting:

> *Nurse: I think the frequent flyers are getting a little more violent than they used to be. They're more likely to take a swing at you. I don't remember that when I first started here. They kind of appreciated you more.*

This atmosphere of violence contributes to an unsettling mood of mistrust and fear. To stand out too much is to feel oneself a potential target. Thus nurses, like many of the patients I interviewed (see Mike's story, Chapter Nine) cultivated a certain stance of anonymity and caution.

> *Nurse: I've been threatened enough times here. I have a private, unlisted phone number. I don't display my last name and I don't wear a name tag. (echoed by 2 other nurses in this small group discussion and by many others at the other site)*

Such a stance may unintentionally reinforce structural inequalities between providers and patients, contributing to the anger many of these patients feel and sometimes express. The nurse knows the patient's name, but the patient is not necessarily permitted the same privilege. Many have commented on the way patients are stripped of their identities on entering hospitals, leaving behind clothes, familiar possessions, and family or friends in many cases. Here the patient is stripped even of the ability to call providers by name, as well as the ability to hold providers accountable for their actions as individuals. In this atmosphere, patient and provider lose sight of their commonality and their uniqueness.

"Frequent Flyers" as Threats

Nurses not infrequently linked the narrative topics of the threat of physical violence on the job and their experiences with "frequent flyers," although this perception was not universally shared. For patients, the ED was a place where they could let their guard down for a little while and feel that no one was likely to hurt them. An orderly drew the link between these apparently disparate shared experiences:

> *Orderly: When they come here, they know that there won't be any violence--you know, against them. Where in other places, they may be hit and beat up, but they know they won't be beat up here.*
> *Nurse: They may get a cranky nurse, but--*
> *Orderly: They can also express their anger here, also...They can express a little anger here without getting a severe retaliation. They know that. So if they want to let out a little, let off a little steam, they can come here.*

But this letting off of steam may pose a threat to caregivers, as the following story from a nurse shows:

> *Nurse: Yeah, just because, I think, you see the absolute worst people can be and you're subject to so much verbal and, um, quite frequently, you know, physical threats. And I've been hit twice too. But I think you really, you know, you don't, you have a whole different space you feel comfortable with people in. And it's weird, I'll be out like with my friends and we might see a really strange or bizarre person and I'll kind of be watching them out of the corner of my eye because I start thinking of like what could happen if that person just happened to go off and you were the wrong person in the wrong place at the wrong time. Because the second time I got hit, I just happened to be walking by a patient. He wasn't my patient; I was just walking by, I was just the wrong person, wrong place, wrong time, and I was the one he*

> *picked. It could have been anybody walking by this guy. And I think that now, whereas my friends might be chuckling and laughing, I'm, I'm uncomfortable, you know; I'm wary, anyway. So, I don't know. I think we tolerate way too much abuse around here, though, and by tolerating that, we just perpetuate it. I think, um, it needs to be less tolerated, to the point of if you're screaming, yelling, verbally abusive, you're out of here, period. I mean, not if you're like drunk or under the influence of something, that's different. But if you're at the point where you're sober, you know what you're doing, it just should not be tolerated. End of story.*

Anger is a signal of moral infraction and a substitute for feelings of helplessness for both patients and providers. Anger involves assertion of the self, the outer limit of the territory wherein moral discourse with others is still possible. This nurse's moral outrage at the injustice of being assaulted by someone in the absence of wrongdoing has made her feel different in the world. No longer protected by the veil of innocence her friends still wear, she now finds herself more vigilant, more aware, and less relaxed, especially around those who look "strange or bizarre." She shares this experience, and this understanding, with many of the patients who are "frequent flyers."

Baier (1994) notes that the existence of a category of job, with its customary cultural expectations, "creates a climate of some trust in those with that job" (p. 111). I would also suggest that it creates the expectation of a corresponding trust in those for whom the job is done. When our trust is misplaced, we react with anger (See Chapter Eight). Violence, the breakdown of moral discourse, exemplifies a failure in these relationships of trust and connection. The problem of violence against caregivers, as policy problem, is of very recent social construction, corresponding temporally with dramatic shifts in the ideology and economics of health care and suggesting the possibility of connections between "patients" becoming "consumers" and the breakdown of trust between patients and caregivers (Malone, 1994).

"Frequent Flyers" as Allies

However, these patients were not always a threat, as one nurse's story revealed:

> *Nurse: [He was] a boxer. And he, he looked like a boxer. And, let me tell you, his brain acted like a boxer. He was pretty punch happy... But he would come in—I mean, he was a, he was really a bull of a man. He had more muscles than you know what to do with. And even for a sort of transient, street-type person who had an occasional home, he kept himself up very well. But he had a drinking problem. And he would always come in and he would want—you'd give him some Maalox or something. He thought it was mint gin. So he'd come in for his dose of mint gin, which made his stomach feel better. He never really liked gin but he thought that mint gin was pretty good. But he, uh—*
> *Int: That's the first time I've heard that one.*
> *Nurse: I know. I thought—mint chalk, to me, but mint gin to him. He thought it was great stuff. And uh, he actually— he saved my life out in the waiting room one evening. I went out there and there was a really agitated group of people over something or another. And this one guy came at me and was going to punch my lights out for some unknown reason; I didn't even know who the heck he was. And Gene pinned him against the wall. Grabbed him and just picked him up about three feet off the floor and pinned him against the wall, and informed him that he would not hurt his nurse.*
> *Int: Oh, really. So he really—it wasn't just that you happened to be there. It was definitely related to his nurse and—*
> *Nurse: Yeah. And he was always very protective of the staff. If there was any trouble, and Gene was around, Gene would be protecting the staff. Whether he knew anything about it or not, it didn't really matter. He was sort of like your own personal security officer when he was hanging around.*

Here the "frequent flyer" shows up as an ally, not a potential enemy. He has a role in the way things work in the institution. Gene's dose of "mint gin" carries a powerful symbolic message of protective comfort and healing, and Gene responds to this message with an attitude of unquestioning loyalty and reciprocal protectiveness. As discussed elsewhere, this intense loyalty to the institution of the hospital and to ED staff in particular was common among patient participants, even when they felt they had been personally mistreated in some way. Providers maintain a curiously ambivalent relationship with these patients: they resent their "un-fixableness," yet they appreciate their loyalty; they grow weary of seeing them for the same things over and over, yet they are gratified when patients remember them; they vaguely mistrust them, but they claim to "know" them; they feel as though their efforts are futile and yet they still hold out hope, sometimes against all apparent odds. Sometimes they even like them.

> *Int: Do you get attached to these patients?*
> *Nurse: (laughs vigorously) Uh, no, not really. (laughs again)*
> *Int: No?*
> *Nurse: No, not really.*
> *Int: Well, I just asked that because somebody else said, you know, you do get kind of attached to them.*
> *Nurse: You do--, I wouldn't--the term 'attached' maybe is not the appropriate word. Um, you kind of, you know, actually, Jamie, I really like her. You know, and she's actually very nice and every time she's here, you know, we chat and joke around. And, um, yeah! And I* <u>*do*</u> *like her. I mean, I would definitely prefer that she not be here, you know, for obvious reasons. Um, but, yeah, you know, a lot of them are actually very pleasant. Ben was always very pleasant. You know, he wasn't one of these gross people that just cussed you out and spit on you all the time, you know. He was always very nice, um, yeah. So there are some of them that, you know, it's like, oh, God, you can't believe that they're here again. But, you know, they're nice enough, you know. You get along with them.*

The importance, for this nurse, of drawing a distinction between being "attached" to a patient and "liking" a patient seems to be related to a distinction between how she feels about "frequent flyers" as a group and how she feels about specific "frequent flyers." Asked the general question about the group, she adamantly denies attachment, quickly distancing herself. However, once she begins talking about specific patients she refers to by name, she seems to soften her stance, using the word "actually" three times as she modifies her previous assertion of separateness and describes a relationship. This distinction suggests a struggle to reconcile the socially embedded distancing from "outsider" groups with the moral traditions embedded in nursing practice, which call upon the nurse to engage with patients as individuals.

Caring as Vulnerability

A nurse who has worked in the ED for fourteen years bitterly castigated "frequent flyers" in a conversation with me, but her rage, I came to understand, covered over anxiety and unresolved grief.

"I resent the hell out of them, "she said. "I *hate* David [an alcoholic patient who came in frequently]". I reacted with some surprise at this statement. "That's because you're not here all the time on nights," she said, "when you have people who are really sick and hurt from a car accident, or something, and you can't take care of them because you're trying to deal with drunks." Her bitterness was clarified by a discussion of a man she used to work with on the night shift, a mentor of hers, "a great nurse, and a wonderful person" who died of AIDS last year. "And I look at some of these people, and they're just subhuman, and I think, [the nurse], who was a great person, is dead, and they're alive, and they're just a drain on everybody." [From Fieldnotes]

Several aspects of the vulnerability this nurse feels are revealed in this brief conversation. First, she alludes to the vulnerability providers in this setting feel when they have too many patients, their worry that something may be missed, that someone may be harmed because they were too busy and overwhelmed to notice or intervene. Secondly, there is the helplessness of being unable to repair in an ED setting lives so fractured by alcohol. Third, she refers to AIDS, a real and constant risk in a practice wherein blood and haste combine. Finally, she recalls her peer, who died, bringing the possibility of death up close to her and forcing the confrontation with her own mortality in a way that the death of a patient rarely could. She rages at the apparent injustice of fate and her own powerlessness to change it.

Caring is often difficult, but it is especially so when those for whom one is "ordered to care" (Reverby, 1987) are experienced as obstructions, threats, or drains on scarce resources, as "frequent flyers" often are. It is also made more difficult by the absence of institutional and community resources to make caring practices possible and likely to occur. Fiercely negative moral evaluations of patients serve to maintain the patient's otherness as protective distance. But such a stance also prevents providers being recognized as caring and compassionate (See Chapter Eight) and may contribute to provider "burnout" (Benner & Wrubel, 1989; Scott, Aiken, Mechanic, & Moravcsik, 1995) and, quite possibly, to patient violence.

The primacy of the violent, sudden and dramatic in the ED setting can obscure the significance of other patients who are more slowly, subtly dying. This was the case with many of the patients in my study. It also means that those who appear to be hastening their own deaths may be the target of providers' frustration and fury. Matthew is such a person.

Paradigm Case: Matthew

> *Well, I'm gonna--I'm, I'm, I really wanta stop drinking. (pause) I mean, I--actually, I'm lyin'; I really don't* <u>*want*</u> *to stop, but I mean, well, if I don't stop, I had one doctor tell me that I got six months to live, and I had another doctor tell me I was at--no more than two years--and it's been six months, a little longer than six months, this, 'cause they told me this in January (sigh).*

Matthew's name first came up very early in the study, before I began interviews, when a charge nurse was lamenting his repeated admissions to the ED for alcohol-related problems, and the apparent futility of trying to help him. Many other nurses independently mentioned his name when they learned about my study. Like many of the chronic alcoholics I interviewed, Matthew rarely brings himself to the emergency department. Rather, he is brought by ambulance after suffering injuries related to drinking, seizures from not drinking, or assaults by others who rob and beat him. Sometimes he is brought in simply because he has been seen lying in the street, and passersby call the ambulance, assuming he is unconscious rather than merely sleeping.

I first encounter Matthew at about 8 a.m. as he lies on a gurney in the ED. He has been in the ED since 11:30 p.m. the night before. His blood alcohol level on admission was 560. A florid-complexioned 39-year-old man whose face is pocked and scarred, Matthew has an air of innocence and lostness about him, a hopeful eagerness that reminds me oddly of dogs at the pound. He is rubbing at his left eye, which is reddened and bloody looking; he has a prominent black eye from "falling in my apartment." He constantly picks and scratches at his head, neck, face, and body and seems utterly unselfconscious about this, dropping pieces of dry skin over the side of the gurney by where I stand. He gazes off most of the time as we talk, into the middle distance, but he does occasionally make eye contact when a point seems particularly important to him.

Matthew lives in a low-rent studio apartment on Supplemental Security Income of approximately $600 a month. He does not receive this money himself; his father is his payee and comes to his place every two weeks to bring him groceries and an allowance of $50 spending money. His father also buys him a certain amount of beer, because his mother apparently (and mistakenly) believes this might keep him from drinking vodka, which she perceives to be a greater evil.

Matthew's relationship with his family is complex and, one guesses, difficult for everyone. His father was a violently abusive alcoholic who beat his wife and children until he finally stopped drinking fifteen years ago. Matthew was the oldest of five brothers, one of whom was a hemophiliac and died several years ago from AIDS contracted from a transfusion, leaving a wife and three small children. The oldest of these, a boy, was taken in by Matthew's mother after the brother's death.

Matthew visits the ED twice a month or more; sometimes he appears several days in succession. He stood out as a study participant because for providers he seemed to typify the "frequent flyer" patient. His interviews were studded with long narrative accounts centering around the twin themes of risk and rescue. One of Matthew's most vivid and revealing narratives concerns his brother's funeral, which took place on Matthew's birthday.

> *Matthew: I had to spend my whole birthday--at the funeral home, and my mother's a NUT for takin' pictures of dead bodies. So I'm, I, I, I've already got it planned out, I just haven't done it yet, I want to be cremated. 'Cause I don't want her havin' my pictures in a, in a casket, you know; I mean, that is--to me that's gross, for one thing, and she--she spent about, after the funeral was over, she spent about a good hour in there, at least, takin' pictures, and takin' pictures, and...and I would, I would prefer to be burnt.*

The image of Matthew's mother mourning for her dead son while her living son's birthday goes unrecognized seems to characterize Matthew's understanding of his relationship with his family, which is rather estranged despite the fact that he sees them often. He is almost an outsider, the "black sheep," boxed into a small room and brought basic sustenance when necessary. This story also makes explicit Matthew's expectation that he will die before his parents do and suggests an underlying anger at the notion that his mother might spend such intimate time with him only when he was dead.

He stays at his parents' house occasionally, usually when he wants to try to dry out from drinking for a while, but he now must pay rent and stay in the same room with his nephew, since his mother has given Matthew's old room to his 32-year-old brother.

> *I had my own room, in the den...I had it for twenty years. But then my Mom said, 'Well, I got two beds in there now,' in the other room, and um, she*

> *wanted to give it to my brother Michael. So he's got it nice, fixed up--and he's, he's a hustler, he's always out there paintin' houses. And he's got it. And...he stays clean. He's got the room fixed up better'n' I ever had it fixed up. Me and my brother, the one that died, we used to sleep in there when we first moved there, when I was fourteen.*

One senses that Matthew feels displaced by this "good" brother in the affections of his parents as well as from his room. For his part, Matthew reveals a complicated mix of furious resentments and desperate longing for parental love which culminate in behavior that to an outsider appears self-destructive but not really irrational. For example, in a story which he introduces by saying it is "the worst time" he can remember, he makes a very calculated decision that ultimately results in his requiring rescue. He dresses up nicely and goes into a store, where he drinks a quart of Jack Daniels whiskey in ten minutes, setting the empty bottle back on the shelf. He is very careful that he does not arouse suspicion, to the extent that he goes and buys some milk so he will not be seen leaving without buying anything. He falls into a coma just outside the store and remains comatose in the hospital for four days.

In this story, he brags about his strength as a drinker.

> *It took me about--four to five shots just to knock out a, a whole quart. You, you gotta be a strong, strong man to drink it. I never, I could never, and the worst thing was I was in a coma for four days, in the hospital, right, in fact, right here. I was in a coma 'cause I, I, I just drank too much too fast.*

Being able to drink a lot is in some way both a test and a proof of his ability to survive. Here he *misjudged* his abilities, leading to a need for rescue. This is a testing the limits story: the limits of his body's ability to tolerate alcohol, the limits of his ability to fool those who are 'running the store,' the limits of society's tolerance for his behavior. In the context of Matthew's family history, such behavior also suggests the possibility of a deep yearning for parental care. This possibility is given added weight by Matthew's response when asked if there is any specific time he has gone to the emergency room that stands out in his mind.

> *Matthew: Yeah, when I had a, when I have seizures.*
> *Int: But I mean, can you tell me a story of a specific time, does any one time stand out?*
> *Matthew: Yeah. 'Bout two or three weeks ago. I was with my--my parents brought over the food. It was a Saturday. But I, I said, I'm, I'm, --cause he didn't buy the beer yet. He had already bought the food, but he didn't buy me the beer. So they were, he was takin' me to the Safeway up here, on (street), and um, he was buyin' me a couple of six packs, but I got--I told my Mom, I'm ready to have a seizure, so she bought me a forty ouncer. Country Club. And I went outside the door, cracked it, took one drink, and fell out and had a seizure. And she--and they called the paramedics. They stayed here all the time I was in here, too, though.*
> *Int: Your parents did?*
> *Matthew: Yeah. They stayed...'cause he--my Dad don't like comin' over here at night.*
> *Int: So--this visit kinda stood out because they were here with you, or what was it that made that visit to the emergency room stand out, particularly?*
> *Matthew: Because I was with my parents. And--I was tryin' to down this beer. And I had that one swallow and I fell right out. But they stayed here all the time. I was right here in emergency room. One of these rooms. And they kept comin' and visit, and then go back out. Come back in, and...and I was here 'til, I don't know, probably eleven or twelve at night. Yeah, 'cause I have bad, bad seizures.*

What stands out about this visit to the ED, among all the visits Matthew has made (over 30 during one twelve-month period) was his parents' presence, their recognition of and responsiveness to him. His face changes, his expression becomes sweetly boyish, as he tells me this story of being watched over by--attended by--his mother and father. Given his descriptions of a childhood characterized by family conflict and violence, and his displacement from his accustomed room in the family home, this episode reveals

Matthew's yearning for the kind of protective safety zone one only experiences in the naiveté of childhood.

It also centers around one of Matthew's greatest fears: the seizures he experiences when he stops drinking. Seizures recur over and over in his talk as significant events.

> *Seizures, boy, you can, you can die of havin' a seizure. Or go in comatose, and never come out of it.*

Seizures thus assume a significant symbolic place in Matthew's life and a paradoxical one. Perhaps at no other time is a human being so unable to control his body as during a grand mal seizure; yet for Matthew, a seizure is most likely to occur when he does exert a kind of control and refrains from drinking. When he has a seizure, others rescue him and take control, at least for the moment, but this perhaps comforting assistance is bought at the price of an immediate threat to his life.

This points up the absurdity of the standard emergency department discharge instructions he is given to "stop drinking," routinely written without acknowledgment that following such instructions may result in real harm. Viewed from the perspective of the severely alcoholic patient, such instructions are at best naive, at worst cynically punitive. They serve to reinforce the rationality of biomedicine in that they are based on an abstract "preoccupation with causes" (Kirmayer, 1988, p. 82) rather than on a concern for this particular patient's needs, difficulties, and possibilities in the situation. Matthew is desperately struggling to stay afloat atop a makeshift raft in a flood-roaring river, while those safely standing on shore call out to him to stop.

Misjudgment of risk and subsequent rescue/survival are dominant themes in Matthew's narrative. In three separate, complete stories, he tells about incidents of danger. In each, he places himself at risk, a risk he realizes later, he misjudged, leading to consequences different than he had anticipated. The episode of drinking the Jack Daniels was one of these; in another, he goes swimming in the ocean under less than ideal conditions and is brought to the ED. "They survived my life," he says.

> *I had bugs at the time, critters?[body lice] And I know that salt water will deaden 'em. So, I take off my shoes, and go out with all my clothes on. But normally the tide goes to the right, but I didn't figure it out until I got about twenty feet out, that the tide was goin' to the left, so next thing I know, I'm, I'm, tide's pullin' me over here to the, to the coral reefs...I cut up my feet, and I, and I tried to get out of the, out of the water, hard as I could, and--'cause I'm a good, I'm a good swimmer, I got, I got pictures of me divin' off of two-story apartments, right into eight feet of water. ...But um, but I w--I w--, I was totally, really messed up. And um, so, I was tryin' to get rid of them bugs, without usin' Kwell Lotion....And I ended up at ..._____ Hospital. And they, and they, and they, uh, debugged me, and they said I was, I was asleep for uh, eight, eight, uh, nineteen hours. But if, oh, what h----, oh, what happened was, when I was in the water, I passed out. I, I just couldn't, I couldn't, I couldn't make it back. And it wasn't that far, you know, and normally, and even if I woulda been in swimming trunks, I--I coulda done it even if I wasn't loaded. But um...*
>
> *Interviewer: So you were loaded, at the time?*
>
> *Matthew: I wa--I was. I was plastered.*

This story seems to capture a key element of Matthew's self-understanding in terms of being inexorably pulled toward his doom despite his own struggle to save himself. He views his alcoholism as hereditary and his chances of overcoming it skeptically. He wants to be regarded as a "strong swimmer," but worries that ultimately he will fail, that he will not be good enough or strong enough, that the tide will be too strong.

In the emergency room, "they survived my life." It is interesting that he uses the word "survived" instead of "saved," given his careful monitoring and correction of his words and pronunciations elsewhere in the interview. "Survived" seems to imply a more temporary respite; "saved" has a finality the other word lacks. His rescue is tentative, not for good. His culpability in the situation, in terms of his intoxication, is very secondary in this story, as in all his stories, perhaps because for Matthew, drinking is a constitutive practice rather than an intermittent, conscious choice.

Like many of the other alcoholic patients I spoke with, Matthew places great emphasis on eating as a survival practice, and his stories about cooking for himself at home are rich with detail. Eating is critical and sometimes very difficult for these patients, since gastrointestinal symptoms and/or illnesses are common; they also suffer from severe nutritional deficiencies. Matthew has also learned, by being robbed, not to invite strangers to his room to drink, and he has developed a keen sense of anticipation for the likelihood of seizures and tries to take care to ensure that he is somewhere where people will help him. He does not buy bottles larger than half-pints, having learned from the experience of drinking too much too fast that he can more easily be robbed under such circumstances. When he does not have alcohol or money, he panhandles, and has developed confidence in his ability to get enough money for a bottle when he needs it and a repertoire of skills that replicates that of upper class businessmen. For example, he notes that

> *Matthew: Once I start out, once I got some change in my hand, it's easier to make the money. But when I start out when I'm broke, I'm flat broke, it's harder to get the money.*
> *Int: People are more likely to give you money if you have a little bit already?*
> *Matthew: Yeah.*
> *Int: So do you save a little by to—*
> *Matthew: Well, um, well, sometimes, yeah, I'll stay there a little longer [after he gets enough for a half pint] and that way I'll get at least another 15 cents or a quarter, so I'll have something to start with when I get through drinkin' the half pint.*

"It takes money to make money," the saying goes, apparently even at the most marginal economic level. Since, for Matthew, drinking is necessary to ward off seizures, he works hard to ensure that he has enough to drink, belying the common perception of chronic alcoholics as lazy or disorganized. Drinking is not an indulgence, for Matthew; it is a necessity of life, as basic as food or water.

In the longest and most fully developed of the three narratives that anchor this interview, Matthew tells about an earlier period of his life, when he joined the service. "I joined specifically just to prove to myself that I can handle goin' through the Army." However, again a misjudgment appears. He knows that the guys next door are selling marijuana and cocaine; he gets to know a guy across the street who one day asks him if he knows where he can get some marijuana; "the next thing I know...they got me for conspiracy." According to Matthew, he was given a choice about whether he would stay in the service or be discharged, but vaguely described death threats "scared" him and he decided to get out, not without some regret: "Once you're in there six months, they give you your first, your first stripe. So at least I had a stripe on me for um, twenty-eight days," he says, ruefully.

Having left the service, he "said heck with it. I had...my girlfriend, and I had a nice apartment in [town], and... a sixty-nine Chevy...which didn't last two days." This seems to have been a brief, golden moment of happiness for him in which he had everything. But, he admits, he "fucked it up."

> *Matthew: I was goin' out to (town). And I was drinkin' hundred proof Southern Comfort. And I said, Georgia, oh-oh, we gotta go back, so I, I, I pulled off the road into a pull-off space...it was a lonely road, but well, it was the only car that I ever had, I've owned at least fifteen cars in my life, but it was the only car that I didn't see how fast it'd go. It only had a three fifty in it. Because I'd just--bare--I'd be barely pushin' the throttle down, and I would be doin' ninety to a hundred miles an hour, so I said, oh, man...*
> *Int: So you wrecked it?*
> *Matthew: Hold on, let me, let me explain...*
> *I: Okay.*

Matthew: Okay. I went on, I went on a road that's, that a car or a truck'll come by every fifteen minutes. It was a, it was a nice lonely road, but then, had a l-o-t of little sloopy hills, you know? But you get, you can do ninety to a hundred miles an hour, no problem. And I came up on this truck, and the truck was goin' up the hill, and he was only goin' about ss--fifty or sixty miles an hour. And then um, I made a f--I made a s--fast, split decision. Should I go around to the left, or around to the right? 'Cause to the right looked--'cause I was doin' about seventy-five or eighty miles an hour, and...I said well, the hell with it, I'll, I'll just take my chances goin' to the [left], and I--I'll never forget this, never, you never pass no big truck goin' over a hill where you can't see the other side. 'Cause as soon as I started to, startin' to pass, this little Volkswagen comes flyin' this way, and I--and I had to make a split--even though I was... pretty much plastered, I said, man, if I hit this guy head on, I'll k--, I'll hit, I'll kill 'im. 'Cause I was in, I was in a sixty-nine Chevy, which was a, you know, three times as big as a Volkswagen. And, so I was slammin' the brakes on, and I said, 'cause there was enough room for both of us to go by, but I didn't know if he was, noti--well, so, I--I had to make a fast decision, and slammed on my brakes, and got around n' to the right of the truck, and I--I thought I was all cool, and I, and I hit this little old ditch, 'bout two feet, and did a complete flip upside down. And, and this is one day after I got out of the army. Did a complete flip--I did, I did such a complete beautiful flip that all's I did was smash the driver's side, where I was at, and Georgia's side wasn't even touched. And I just (sound) flllwhaam! and slid about twenty or thirty feet. I don't even know how far it wa--uh. Then I tried to figure out how'm, I said well, I, I can talk my way outta this. It took the, took the um, state troopers, as they're called out there, about twenty...twenty to thirty minutes before they got out where, where I was flipped over. I almost had the guys that--in the truck and in the Volkswagen 'cause they were right there, standin' at--'at's, 'at's all I could see when I...I said 'Georgia, you all right?' but I, I totaled the car out completely, and...

Int: But she was okay, huh?

Matthew: Yeah! She was all right, but she was sore, you know. And all, and all's I did was just cut my hand...

Int: Wow.

> *Matthew: ..finger or somethin', and that was it. So...and plus I had at least a half a tank of gas, and uh, the police said, 'man you're lucky you're alive, man, that thing coulda blew up on you, man.'*

Matthew resists when I naively try to jump to the end of the story with a summary question, suggesting that there are elements of the story that he views as essential to its understanding by another person and that this story has particular significance for him. This is not merely a story about wrecking a car. Instead, it is a story of calculated--perhaps, to him, even heroic--risk in which his drinking is mentioned, but almost peripherally.

It is important enough to be mentioned twice in Matthew's narrative that this story takes place on a "lonely" road. As in the story of swimming, he sees himself struggling alone and heroically against circumstances he cannot control. His actions are characterized as a series of split-second decisions in which he skillfully attempts to keep going full tilt and avoid hurting others. He gives no indication of concern for himself until the accident has happened, at which point his concern is how he can talk his way out of the situation with the state troopers.

When Matthew speaks of automobiles, as he does several times in the interviews, he becomes almost wistful. The cars show up as a bit too powerful for him to control, associated with injuries or losses for him but with success for others like his father. His last car was repossessed, "the only car I've ever had that I never hit something with it." Cars, in our culture, are possessions that suggest success, mobility, freedom, and independence. The car is a symbol for both the autonomous, objectified self (Gordon, 1988) and the body-as-machine (Kirmayer, 1988). Insofar as the car stands for the self of rational autonomy and the body that can be mechanically repaired, Matthew's story reveals a profound despair over his inability to attain either. Both his dependence on alcohol and the seizures that occur when he tries not to drink mean a loss of control. Either way, he loses.

The narratives of risk and rescue, however, also suggest the hope for a possibility of survival, of some miraculous beating of the odds. He emerges from the wreckage with only a scratch; he defies others' grim prognostications. His favorite Bible stories, he volunteers, are Daniel in the lion's den, wherein faith saved Daniel, and the story of Peter, who lost his faith and sank in the water.

> *Matthew: I like Psalms, and I like Matthew, Mark, Luke and John. Yeah, 'cause, y'know, Jesus Christ, well, according to the Bible, he raised two people from the dead. He--he was always healin' people. (pause) But they crucified him. And he came back to life in three days, according to the Bible. And (pause) and according to the Bible, he also walked on water (chuckles). And Peter--he'd go, 'Peter, come on out!' Peter went out, but he, he lost his faith, and he went and sank, right in the water. They were at the, they were at the Red Sea...and then one time it was stormin' like hell, and tearin' the boat apart...and Jesus Christ was in there sleepin'. And they were all, these Apostles, or Disciples--woke 'im up. And he, he said--puts his hand out--calm, calmed the wind, you know, 'til he stopped the whole, the whole storm.*

Hope, in Matthew's world, comes not from himself or any actions he could take or not take, but from someone outside himself who will step in and calm the stormy waters of his life, who will recognize his need for rescue and healing. Matthew's stories reveal an underlying understanding of his deteriorating condition and the increasing stakes of his way of life, but he does not show up in them as able to change the course on which he seems irrevocably set, nor does anyone else seem to truly believe in that possibility, since even his parents continue to bring him alcohol and his social worker has not followed up on his failure to attend required meetings.

Asked about his implied expectation, revealed earlier, that he would die before his parents, he replies:

> *Matthew: Um...(long pause)...Yes. To your uh, (long pause) ...well, I guess you can call it a question. Yeah, I don't--I don't plan on bein' alive, I'll be, I'll be lucky if I even hit forty years old, and I only got two more months 'til my birthday.*
>
> *Int: Now, why do you say that?*
>
> *Matthew: Well, because...I don't know, I've had different opinions from different doctors; one doctor told me when I was thirty years old, if I keep drinkin' the way I drink, I'll be lucky to live two years. And then another doctor told me, about...six months ago, if I keep drinkin' the way I drink, I'll, I'll have, I'll be dead within five months. Then another doctor told me, if you keep drinkin' the way you drink, you have two years. So--all right? But the main thing is, that I've learned, is that, is--you gotta eat.*

In the same breath in which Matthew darkly predicts his death, he holds out for himself the possibility that others are wrong about him, after all, and that he will survive. Even as he confronts a shrinking temporal horizon, he continues to project himself into future possibilities (Weiss, in progress). The ambiguity of opinion about his chances is understood as a warning, but also as a fragile but significant reason to hope.

In a way, he seems to have taken up his drinking, which from an outsider's point of view is his biggest problem, risk factor and weakness, as the way he challenges and tests himself and learns important survival skills in a world that is unpredictable, untrustworthy, and dangerous. These survival skills--"you gotta eat," "don't invite strangers to your room," "don't drink too much too fast" may sound obvious, but for Matthew and others like him they are hard-won lessons, moral tales told again and again to remind oneself of rules for safe conduct when drinking.

Drinking is the constant context of his life. Matthew's stories are indexed by what he was drinking at the time. Asked what would be missing if he stopped drinking, Matthew gives a disarmingly simple yet illuminating reply:

> *Int: I'm asking about what you would give up, in terms of how your life is. How, what, what would be gone if you gave up alcohol--besides just the alcohol?*
>
> *Matthew: (long pause) Mmm....Alcoholism.*
>
> *Int: Hm?*
>
> *Matthew: Alcoholism. Because, you know, once you're, once you're an alcoholic, I mean, you can't just stop it, and just say no--well, my Dad did it, but he didn't do it 'til I was twenty-five years old.*

Because Matthew's entire existence is structured around his drinking, the possibility of its absence suggests a gaping hole in the thinly-woven fabric of his life. Asked to tell me about a typical day, for example, he describes going to breakfast at a nearby mission, tucking a bottle of juice surreptitiously into his coat so he can sell it later to get money for a bottle of vodka, then selling his extra groceries or panhandling for the rest of the day to get money for the three half pints he needs to feel "decent." In all these activities, he displays a remarkable resourcefulness and even inventiveness that in another context would be highly regarded in our culture.

His drinking serves to define limits and boundaries for himself in a world that is otherwise fragmented and agonizingly lonely. His drinking both constitutes and organizes his daily activity. It is difficult to imagine what he would do without it, and Matthew himself has only the vaguest of notions of "getting a girlfriend" if he quit drinking, but he is unable to project himself into the future beyond the most general, global wishes.

Matthew's drinking can be further interpreted as a way to maintain a family identity and connection and to promote the kind of nurturing or at least caretaking behavior, especially from his father, that was clearly lacking in childhood. Drinking is a family legacy (Plager, 1995).

> *Int: What are your goals? (pause) Do you have plans, or goals for the future?*

> *Matthew: I understood what you said, when you said goals. I'm, you know, I'm not, I don't consider myself unintelligent.*
>
> *Int: I don't either.*
>
> *Matthew: But I don't consider myself 'telligent enough to stay away from the booze. 'Cause um, to me it's hereditary. 'Cause my Dad was an alcoholic, his Dad was an alcoholic, I'm an alcoholic, my brother was an alcoholic, the one who died, [other brother] he stops, he stops drinkin', I'll give him credit, he. he stopped for two years. Then he falls off the wagon...*

. Asked about goals, Matthew answers with the precluded possibility of not drinking. Not drinking, as already discussed, puts him at risk for the terrifying seizure from which he may not wake up. Drinking is also the way Matthew at once identifies with and expresses his rage toward his father, for whom one imagines it must be very painful to see his son this way. Drinking is necessary to "feel decent" about himself; it is also on account of his drinking that his parents visit twice a month, that they came to the hospital at least once. Drinking creates the context within which he shows up for others as someone who needs care.

For Matthew, the emergency department is a kind of constant backup system for when the family system is unavailable and his risktaking/testing behavior leads to injury. It is a safe, relatively stable place he "ends up" where he sometimes has an opportunity to figure out how he is doing. He is rescued there, though only temporarily. Matthew does not completely trust the personnel in the ED, nor does he "really" know them, but he is somehow reassured by the fact that they "know" *him*. The emergency department is itself taken for granted, almost entirely in the background for Matthew. It shows up in his narratives only in reference to the conclusion of situations of extreme risk and breakdown, and then only in very general and muted ways; yet, as I later learned, the ED was a place where both he and his family continually sought resolution of their mutual despair.

True to his predictions, Matthew died not long after his fortieth birthday, about six months after my last interview with him, of injuries from a fall after drinking. His passing was widely remarked upon by the staff, whose comments reflected a variety of interpretations of the social and personal meaning of his death. For both Matthew and his family, the ED was a support system, albeit not always an adequate one, that helped them cope with their mutual feelings of helplessness. For the staff, Matthew was at different times an object of pity, a detestably dependent drunk, a touchstone of familiarity, and a disruptive obstruction. He was also, as will be discussed below, a legend.

Matthew, who desperately longed for someone to care for him, found himself trapped by his overwhelming need for rescue, yet that need was the way in which he could be seen as needful. His family, wanting to help him, found themselves trapped by their ambivalence about his dependency. Health care providers, drawn into the cycle as rescuers, found themselves trapped by the model of patient as informed consumer, which assumes a level of autonomy at odds with Matthew's need for nurturance and care.

Matthew's case also brought forth, for me, questions about what alternatives really were available for someone like Matthew, should he sincerely seek to stop drinking. Public insurance programs in the state in which Matthew lives do not cover inpatient medical detoxification programs, and, as Matthew himself made clear, when he stopped drinking, he experienced seizures which were themselves a threat to his life and health. This issue is discussed in more detail in Chapter Ten.

Bearing Witness to Self-destruction and Deterioration

It is agonizing to bear witness to suffering. Witnessing is qualitatively distinct from mere looking; witnessing engages the witness in the suffering as a bearer of truth that the sufferer, being bound up in his suffering, cannot tell for himself. Witnessing is a keeping watch over. Repeatedly, I heard stories of how nurses watched as patients they came to know as "frequent flyers" slowly deteriorated and died. One of these patients was a man I will call Nicky, recalled by a nurse with over twenty years of experience in the ED:

> *Nurse: A young... fellow that I probably started taking care of twenty years ago. You know, probably one of my original patients here, who, at the time, was employed by the post office, which is a pretty good job. ...And for the first several years that we saw him, he was able to maintain an employment, you know, but just was a chronic alcohol abuser. And we saw him, you know, starting out it was more the weekend partying, get too drunk, fall down, get in a fight, whatever. Um, but over a period of time, you know, his drinking started pouring into throughout the week. So we just ended up seeing him a lot. ...Nicky was uh, you know, started out as a pretty nice guy. He was cute and bubbly and fun-loving, and had a tendency to get more happy and more fun-loving, and, you know, as he drank. And all of that changed. You know, his drinking started pouring over into mid-week. Um, and after , you know, probably ten years he wasn't fun anymore. He wasn't cute. He became obnoxious, belligerent..*
>
> *Nurse #2: --and then I think a year ago his mother died. And I think that really pushed him--made him drink more and--*
>
> *Nurse #1: Yeah. He was so far in the toilet by then, though, there was--you know, but he was, he was dirty, he was obnoxious, he was demanding, he was mean, and all of this stuff that used to be fun about seeing him on a regular basis, just went by the wayside because he was really a pill after that. He was, you know, living on the streets and filthy, and very, very obnoxious, and drunk constantly; you'd see him just as drunk at 10 in the morning as you would at 10 at night, and he didn't really have any major health problems, but I think just, you know, nutrition, stamina, everything went by the wayside. I can't remember what happened to him. I think he didn't--I don't think it was anything more than just an illness, pneumonia or something like that. And he died fairly recently.*

As this narrative progresses, Nicky's personhood falters and fades from sight. In the beginning, there is a kind of forgiving understanding of Nicky's problem; he gets too drunk at parties because he's a very "fun-loving" kind of guy. But by the time his mother dies, his personhood is fading in the narrative; he is "obnoxious," "dirty," a "pill." By the end of the story, he has become simply a burden, a dreaded burden. His personhood has been "left by the wayside." This story stands out for the nurse because of the terrible way Nicky disappeared before her eyes, leaving her feeling helpless and guilty that she could not prevent his destruction, that she could not save him.

Nicky's kind of death is not the kind of death the ED is set up to avert. It is too slow, too fraught with contingency; it is a *vague* kind of death, in contrast to the sudden, definitive death against which emergency providers prefer to struggle. In some ways, Nicky's death is rendered almost invisible in this setting, because it has been going on for years. But Nicky's suffering is not invisible. Providers must watch, week after week, as patients like Nicky disintegrate before their eyes from people whom they can enjoy caring for and about to an almost animal level of mere physical survival.

Witnessing as a Moral Act

"Empathetic witnessing is a moral act, not a technical procedure," Kleinman has observed (1988, p. 154). Empathetic witnessing, as described by Kleinman, is

> the existential commitment to be with the sick person and to facilitate his or her building of an illness narrative that will make sense of and give value to the experience. But the practitioner also struggles to model courage and to see it in others...The commoditization of the healer-sick person relationship cannot quantify this aspect of the relationship, which, as a shared virtue, is not captured by a cost/benefit equation or financial bottom line. It is rather the healer's gift as well as that of the patient (1988, p. 54).

The person who observes suffering is faced with a moral choice between taking up the burden of bearing witness by recognizing the sufferer as a fellow human and engaging with him, thereby privileging his likeness over his otherness, or assuming a disengaged stance of nonrecognition in which the sufferer is rendered invisible, wholly other. But patients like Nicky present an incredible challenge to those who would bear witness inasmuch as their illnesses and eventual deaths are commonly viewed as "senseless," preventable, brought on by their own morally suspect behaviors, and the brevity of any given encounter does not lend itself to developing an alternative interpretation.

Aries (1981), in his massive historical treatise on the way death shows up culturally throughout recorded history, suggests that the modern death is a highly managed affair, completely medicalized and thus essentially denied in comparison to earlier eras. The sudden, "tragic-accident" death which we have noted as the model for which the ED is assumed to exist is a technologically challenging event, not always necessarily a morally challenging one. By contrast, the prolonged and agonizing death of a patient like Nicky cannot be medically controlled in the same way; it escapes the technological embrace in which providers find protection; it scrapes raw our moral sensibilities if we let it too close, and patients who arrive daily or weekly *will* get too close.

Stances of Coping

Providers take up various coping stances along a continuum between ongoing personal engagement and disengagement. Pity, for example, seems to occupy a middle position; it permits providers to feel for patients but still protect themselves by seeing the patient as its object. In the following excerpt from the provider discussions, I asked a nurse whom I had observed to be quietly caring with even the most difficult patients about a specific "frequent flyer":

> *Int: And, I mean, do you know him? Do you know anything more about his background or--?*
> *Nurse: No.*
> *Int: You haven't ever gotten that far with him.*
> *Nurse: It's probably kind of unfortunate that we don't. Um, people who I've found that I've tried to talk about background are unwilling to really go into much at all. Maybe if I had more time and more patience or asked the questions correctly, the right way, and more--maybe my voice sounds impatient or they don't--. But when I have, it's a little hard. They're guarded, a lot of them, and maybe it's been unpleasant, their lives.*

> *Int: You seem like you, um, are still able to be very caring about a lot of these patients, whereas not everybody, I don't think, is able to do that. I've noticed that about you.*
> *Nurse: (very softly) Thank you. 'Cause it's hard sometimes.*
> *Int: Yeah, it is. I mean, how do you do that?*
> *Nurse: I feel sorry for them. I see a really pitiful side and I really do feel sorry for them. I think that they've gotten themselves into--you know, life is hard enough (pause), and these people have horrible background probably, a horrible childhood, a horrible, that's caused them, or just alcohol itself has entered their lives, and they're out of control. I think that's sad. I think it's very sad.*

Here the nurse very clearly sees the patients as persons with failings, but she makes note of possible social causes that render the patients less blameworthy; she also admits her own failings in trying to get to know them better. The patients are not wholly other, yet they are set a little apart as pitiable. Pity thus emphasizes differentness rather than commonality (Younger, 1995). Because providers are not saints, it is not possible for them to fully engage with every patient they see every day, particularly in a setting like the ED where the timespan of an encounter may be only minutes to hours. This calls attention to the way the structural aspects of our institutions of care affect the kinds of care that are possible (Scott, Aiken, Mechanic, & Moravcsik, 1995).

As Real As It Gets.

A T-shirt celebrating the ED services of one hospital reads "As Real As It Gets," and providers take pride in being able to deal with the most ghastly injuries and illnesses, but as Baier noted wryly, "humankind can bear only so much reality" (1994, p. 115). Trying to preserve a space where connection is possible with patients such as Matthew can be emotionally wrenching, especially when there is little public space in which such suffering--and one's own pain in witnessing-- can be talked about with others.

As another nurse described it:

> *Nurse: The thing too, on a regular basis, is that you are bombarded--I mean, for a 12-hour period--you are bombarded on a regular basis. You sometimes see in a 12-hour period and go through a gamut of emotions that people do not see. Regular people do not see in a lifetime. And you're, of course, you know, that's your job. I mean, that's what you do. And you have to realize what effect that has on you and deal with it in whatever way that you do. And, you know, it gets sort of tiring. I mean, nurses are trained to care and, you know, and take care of, but it truly gets bothersome when you're trying to take care of someone who doesn't take care of themselves. Or refuses to take care of themselves.*

Those who will not or cannot care for themselves represent a direct affront to the ED's primary and most venerated mission, the staving off of death at all costs. The heroic mission to thwart death is directly related to the use of medicine as social control. The warding off of sudden death is a powerful demonstration of our ability to control the body; the slow, atechnological death of alienation and self-destruction that patients like Matthew and Nicky display directly challenges and threatens that control.

"They Treated Me Different": Nora's Story

Those who engage in self-destructive behaviors may become the objects of overt hostility and abandonment if their actions are interpreted as challenging the control of providers and their belief in self-control. Nora, a young woman with a long history of mental illness whose voices sometimes prompt her to harm herself, told me about being taken to another hospital ED after cutting herself:

> *Nora: At the [other] hospital, though, they um, because I hurt myself, they treated me different. Like, the doctor that came in to stitch it up, wasn't gonna stitch it or nothin', he said, um, 'cause (inaudible)...And he said, well, he told one of the other persons that was there, he said, 'Well, if she hadn't, if it was an accident, I would stitch it, but because she does it on her[self]--because she just does it on purpose, I don't think I'm gonna do anything. Put a bandage on it, and send her home.' And then when the doctor came over and asked what he thought--planned on doing, and he*

> *told her he thought he'd just put a bandaid on it, and the doctor said, 'No, that needs sutures.'*
>
> *Int: This was a other—another doctor, then?*
>
> *Nora: Yeah. And so, see I don't think they care so much up there. And like tonight, they didn't want me to come in even voluntarily, I have to come in on an emergency hold from mental health.*
>
> *Int: At the other hospital.*
>
> *Nora: Yeah. And they have a, and other hospital emergency room, not here, they told me, (inaudible) got mad at the ambulance people, because they said, 'What 'd you bring her here for?' and they said, 'Well, because she wanted to come here,' and they said, 'Well, we don't want her here.' But here, they always say, 'You can come here, and we'll take care of you,' and, and, that's why this is about the best emergency room, I think, because, and last time I was at the [other hospital] they were very nice, but...they're always nice here.*

For Nora, these experiences stand out because of their dehumanizing character. This experience of seeking aid and comfort and being regarded as an unwanted object is comparable to a child's seeking out his mother after being hurt, only to be met with a slap. The longing for comfort and relief from pain is met with the added pain of injustice. Requesting help makes one vulnerable to the possibility of refusal and rejection. For someone whose fragile sense of self is sustained at great cost, as is often the case in people with serious mental illnesses such as Nora's, such rejection is not only neglectful, but cruelly destructive.

> *Nora: (long pause). I think the one that was the worst...was (softly)when they told me they didn't want me here. Um, that and listening to the doctor talk about me in front of me as if I weren't there, and saying, no, cause this isn't an accident, and I won't take care of her. (inaudible)*
>
> *Int: What did you do?*
>
> *Nora: I didn't do anything, because I felt like what can I say? You know, he didn't want to take care of me; he probably wouldn't want to talk to me.*

> *That felt kind of awful. I mean, if he wanted to talk to me, he would have talked to me, okay, 'cause he's standing right over me talking--about me.*

Here the patient is rendered almost entirely invisible by providers' explicitly voiced refusal of absolution of responsibility for the illness (Lowenberg, 1989) and rejection of her appeal for help. The assumption is that the patient is an entirely autonomous agent who willfully set out to harm herself and that in doing so she has produced an illegitimate emergency. This story shows how the facticity of the injury or illness may be less critical in assessing legitimacy than the presumption of moral causation. Turner (1989), drawing on Foucault, calls attention to the way the body lies at the heart of the social order and is at once both embodied consciousness and the site where social control is worked out. The affixing of moral blame results in exclusion of Nora's personhood from social interaction involving her body (also see Chapter Six).

What is particularly distressing in this story is that no one else seems to have stepped in to assuage the emotional wound created by the doctor's refusal to care. Even the attending physician who demurs against the punitive plan of the resident is not described as having acknowledged Nora as a suffering person in any way; the problem is a technical one, not a moral one. In Nora's story, she is recognized only as a wound, and an illegitimate wound at that. This calls attention to the difference between the mechanical function of suturing a wound and the human practice of providing care to the injured, which involves the skills of attentiveness and recognition (Bellah, 1991; Benner, 1994b; Benjamin, 1988; Taylor, 1991; also see Chapter Eight) and requires time and patience. It also alerts us to the way such moral judgments are not merely the isolated idiosyncratic responses of individuals, but are embedded in the societal coping which the ED itself serves, worked out through the Cartesian distancing of mind from body. Younger (1995) observes that

> The chronically ill are often unwillingly thrown into the position of bearing witness to a truth that society does not want to acknowledge...Suffering discloses the frailty of being, not only to the sufferer, but also to all who enter into its experience (p. 64).

By harming herself, Nora has implicitly refused to abide by the social sanctions prohibiting such public expressions of inner pain and conflict. Her actions tear aside the facade of neutral expertise and expose its moral roots.

"This Could Be You".

When the otherness of the patient cannot be maintained through technological distance, their like-ness can be frightening. One nurse said:

> *Nurse: You know, you can talk about people that are repeaters and the people that abuse the system. But in your weak moments, you can just think that --this could be you, you know. We could have prior to, up to here, or after this, things could happen that would change our lives, that could make you be in the same situation. I mean, no one thinks it could happen to them but it really--I mean, we see people here that are 50, 60 years old that have lost their white collar job, that have gone through all the money they have, and they end up, end up here looking for help. And a lot of times it's medical help, or a lot of times it's to talk to, you know, the social services here.*
>
> *Int: So do you think that that's trying to keep that in your mind--you kind of try to keep that in your mind?*
>
> *Nurse: Oh, yeah. I mean, it just makes you realize how vulnerable that you could be, you know. Just like any trauma patient. You could be the one that's shot. Not every person that's shot or run over by a car and stabbed is, is a gang member. Or doing something illegal.*

Not every "frequent flyer" patient, in other words, can be made wholly other by their blameworthiness. Again, they reveal that they are *like us*. This is the paradox of suffering: it can be either bond or barrier between provider and patient, and it is sometimes both. Rendering the suffering person wholly other helps us cope with our finitude and helplessness, but it also means that we reinforce our isolation from one another. For patients and providers alike, the interpretation of pain and suffering as bond or barrier depends on many factors, including previous experiences with one another, contemporaneous experiences in their own lives, and the general pace and atmosphere of the department. One nurse, speaking of a woman alcoholic who was a frequent ED visitor, said:

> *Nurse: She looked good yesterday, yeah. She came in, uh, I mean, I didn't really take care of her. I just glanced at her. And she looked good. Franny Rose. Why she looked good, I can't tell you. I didn't talk to her. I never talk to Franny unless I have to take something out of her hair, you know--.*
> *Int: Why?*
> *Nurse: --that's gotten stuck in there. She always gets things stuck in her hair. I don't know. I'm always cutting things out of her hair.*
> *Int: Why do you never talk to her?*
> *Nurse: Why? Usually because I'm busy. You know, because I pace myself here. I mean, I don't go out of my way to, uh, (pause). But, you know, there are days when I go out of my way when I have energy to talk more to people. And then there are days that I just can't. I just have to wall off and, you know, I do what I have to do because you have to know, you know, when you can put out more and when you can't deal with these people.*
> *Int: Budget your--.*
> *Nurse: Energy. You have to, here. I mean, you should have seen this place last night. Oh, I mean, everybody was high--everybody was crazy. Everybody was just a lunatic. Everybody was a substance abuser. It was ridiculous. Gruelling.*

Patients who return over and over with unfixable problems to a setting socially designed for the "quick fix" are experienced as morally incoherent drains on the limited energies of providers. "Walling off" is a protective strategy, a defensive withdrawal (Chafetz, 1990), a way to keep oneself from having to take on the pain and terror of bearing witness to suffering that cannot be controlled. Confronted repeatedly with society's failure to provide for basic social needs, by institutional constraints and the rhetoric of efficiency, by the daily evidence of their own finitude and vulnerability, by their helplessness to rescue these patients, and by the occasional glimpse of common frailty, providers may try to transform such patients into a patient version of the omnipotent.

Mythmaking as a Coping Strategy

"Frequent flyer" patients are the subjects of legend for emergency personnel, who recount their survival stories with something akin to awe. These patients are storied as able to withstand tremendous stressors; impugned as "subhuman" in person, they take on almost superhuman characteristics in narratives.

> *Nurse: These people are so rugged to me. You know, even though they're so unhealthy, they're so rugged. And I kind of compare it to like when I took an ecology class, they talked to you about the chaparral and the tundra, the different ecosystems and stuff that fall around this type of plant life. And the chaparral is this really rugged terrain where it goes from, you know, 10 degrees at night to maybe 90 degrees during the day, out in the middle of the desert. And to be a plant or animal life in that environment, you have to be very hardy and rugged to survive, whereas [in] the tundra it's always the same temperature. It's always the same climate, and you don't have to be rugged. Yes, you're living in a harsh condition, but there's no ruggedness about you...And I look at some of these like street people who come in here. I mean, how many times have--I mean, I think some of them have a thousand lives, you know. They're, they're, they're rugged in a certain sense that they live at such extremes in their body. They can go through tremendous trauma and insult. And still walk away from it, and check out a couple days later. But if that was you or me and we just get, maybe, hit by a car, we're very fragile and we die. Because we're not very rugged.*
>
> *Int: So you think that they are actually physiologically adapted, become more--*
>
> *Nurse: They're physiologically adapted to live at any extreme. So something that would kill you or I doesn't kill them. I mean, if you or I got hypothermic to the point of we were, you know, 31[degrees], we might have*

> *been in asystole and unresuscitatable. Whereas, like [female patient], I don't even know if she's still alive. I haven't seen her in probably a year. I know last winter, they ran a code on her for two hours because they couldn't pronounce her because she was too hypothermic. They were trying to rewarm her, rewarm her. Two hours. They got a heart rate back on her. She left a week later. I think maybe she's over in [long term care facility] now... But, I mean, <u>two hours</u>. You or I, we wouldn't come back. But these guys, I don't know, I don't know what it is. And, uh, who else? [Male patient], although I haven't seen him in a while. This was about six months ago, maybe eight months ago. He had come in, been discharged, someone came up to triage, said, hey, there's someone passed out in the bathroom. And they went down to the bathroom. There's [male patient]--*
>
> *Int: The bathroom in the lobby.*
>
> *Nurse: Yeah, in the lobby. There's [male patient] in one of the stalls with an empty bottle of rubbing alcohol which he had stolen somewhere out of the department. It was empty. Brought him to the trauma room. He had a Glasgow[level of consciousness score] of 3. Um, went to the ICU. His blood alcohol level was like .72. They discharged him 24 hours later from the ICU.*
>
> *Int: 24 hours later!*
>
> *Nurse: Yep. He was fine... You know, I mean, we'd be deader than a doornail.*

The patient here is, once again, *not* like "us" in so many ways; the mythmaking function thus serves to exclude these patients from the ordinary human community. Their extreme vulnerability is transformed into a story about their ability to defy death. This allows providers to feel less guilty about their failure to save such patients, since the patients themselves are endowed with such powers. Here the power to save is attributed to the body itself, rather than to intentional mental control of behavior and the body. What such a myth masks is questions about how such situations could be prevented, about the absence of provision for basic, low-technology care, about the social causes and meanings of alcohol and drug dependency.

The Failed Myth.

But the legends cannot be kept alive when a "frequent flyer" dies.

Nurse: I think like everybody--I mean, I felt really bad when he died. Because you always think, oh, these people are going to fall down and hit their heads all the time and live through it. You know?
Int: You hold out this hope that--
Nurse: Yeah, I mean, a hope and it's like they have nine lives, you know, because it seems to me that any--a lot of other people fall down and hit their head once. They're drunk, fall and hit their head once, and they're dead! Well, we see these people again and again and again and it's like they have nine lives. And it's like he ran out of his life.
And there was another nurse that was here, [name], who felt the same way. She said, you know, I felt really bad that he died. I said, you know, I did, too. And she said, I know. It's like he's not going to be here anymore. And I said, I know. And I think it's just we think of your own mortality too. I mean, that's--I don't know. It's weird.

There is comfort in the myth of the "frequent flyer" as superhuman, resilient, able to withstand physical, social, emotional and economic assaults. The reality is more brutal and more isolating for providers who bear witness. Only those who also work in the ED can understand the strange mix of relief, guilt, grief, and fear that providers feel on the death of a longtime "frequent flyer." When the myth breaks down, it leaves those who dare to care very alone.

Constant Contingency

"Suffering must invariably involve the person," observes Cassell (1991, p. vii); "bodies do not suffer, persons suffer." When we allow the suffering of others to show up, when we do not deny it or ignore it, we allow them personhood. We also expose ourselves to pain and fear. Yet there is a way in which our own humanity is diminished when we must shield ourselves--"wall off"--in order to psychologically survive (Younger, 1995). Jack, the volunteer whose practical wisdom informed so much of this study, captured the paradoxical way we must be open to feeling pain in order to feel goodness, or even to feel at all. Talking about his volunteer work, he declared that:

> *Jack: It's taught me morals. It's taught me to be kind to not just to myself and others, but be kind in some situations I don't understand, and that I see happen; I sit there in the background and I don't know how a human being can call himself a doctor or a nurse and treat a patient that way. I don't now how they have the guts to walk in the front door to this place! I don't know how they do. And I've also--but, on the other hand, I've learned that people that have walked through that front door deserve a red, gold carpet. And they should be issued wings at my desk, instead of having to take the elevator. (laughs) How's that, huh?*
> *Int: Talk about that a little more.*
> *Jack: It's just what I said, they're angels. Huh?*
> *Int: Who are angels, the patients?*
> *Jack: No, the doctors and nurses, you know. I'm talking about the [staff], and patients, both. I've seen both being right and wrong. I've seen some patients I'd like to stick their head in a vise and tighten it up and then just loosen it up and let them out and tell them I'll do it again, and I'll do it a little tighter. And they'd rush to get back in there because it felt so good, you know? They're crazy. There's no help, no hope. And I never thought I'd say that about a human being because I never gave them a chance to hurt me. (chuckles) See? I've learned to do that now.*
> *And I can't thank this establishment and the people for showing me that part of life that I never knew existed.*

This is a story about the joy of understanding the other--and the human condition--by allowing one's own vulnerability to emerge from behind the mask of defense and convention. Patients and providers are no longer seen as entirely "good" or "bad"; their shared vulnerability is experienced as a promise, not a threat. In the midst of constant contingency, the promise is the possibility of meeting, the possibility for mutual interdependence, the possibility for compassion (Wuthnow, 1991) in a culture devoted to the pursuit not only of liberty, but of individual autonomy. Sam, whose story concludes this chapter, teaches us something about how such possibilities can be preserved, even under the most difficult conditions.

Paradigm Case: Sam

It all depends.

Sam, a 56-year-old man who calls himself a "tramp," exemplifies the tension between self-sufficiency and dependency even in his choice of words for self-description. He has an identity as a "tramp," a term he uses with some pride; this is qualitatively different than describing oneself as "homeless," which he never does. "Homeless" implies a displacement, a disenfranchisement, a powerlessness that "tramp" does not. "Tramp" suggests a kind of self-sufficiency tempered by circumstances, a cowboy down on his luck. Like the cowboy, the tramp is another American version of the rugged individualist ideal. In circumstances of extreme economic hardship, compounded by physical disability, being a "tramp" (or a "bum," the self-definition offered by another older gentleman who also frequents the ED) calls up Steinbeckian images from post-depression days that are perhaps less culturally threatening and more acceptable than "street person" or "homeless person."

Sam is a grizzled, grey-bearded man who walks with a stooped, shuffling gait. His trousers have the spotted, shiny, almost waxy look that comes from sitting in odd places and wiping one's hands on them many times. His face is wrinkled and slightly flushed and he speaks in small spurts, muttering gruffly almost under his breath, so that in the noisy hall of the ED where I interview him, I must lean very close to hear him, close enough to smell a slight acrid odor of urine, the sweetish scent of alcohol, and, very faintly, the new leather of the thick-soled pair of boots he wears. Yet he also exudes an honesty and a distinct, quiet dignity.

Sam is a former merchant seaman who worked on boats until he was hit by a city bus eight years ago when he was drunk. His pelvis and one leg were severely fractured; he was brought to this emergency room unconscious. His recovery was lengthy; he had to learn to walk again and still suffers intense pain in his leg which he uses alcohol to relieve. He lives on an income of between $600-700 a month SSI.

Sam says nothing about family, denying that he ever married or had children. He makes no mention of his family of origin, either, except to say that he considers that he was "raised at sea"; he went off to sea at 18 without getting his parents' consent. One gets the impression that he has always been a bit of a loner, though he is quite sociable with me and, apparently, with some others, an old sailor now landlocked.

Like many of the patients I interviewed, Sam lives very much moment to moment, day to day; his talk reveals little nostalgia for the past or anxiety about the future. This presentism seems to be necessitated by the constant insecurities of his everyday existence. For example, I ask Sam about his housing status, and he says he sometimes rents a room in the winter, but only for one night.

> *Sam: Only for one night. You know, I can't see rentin' any for more than one night; I mean, I know some joints they charge you fifty a night. Ooh, I love those--but I can't afford 'em.*
> *Int: Fifty a night? Yeah. What if you got something on a monthly basis, would that make it cheaper?*
> *Sam: Yeah, it would, but it's still more than I could afford, you know...See, we get a raise in our check--your damn rent goes up. You know. That's why I sleep on the streets.*
> *Int: Are you happy?*
> *Sam: Oh, I don't know. For me, there's--I'm just glad to be alive. With all I've been through. Hit by a bus--you know. Here I'm tired most of the time--I never get enough sleep. Sometimes I--I lay in this position. And then this side starts hurtin'. So I roll over on my back, and my back gets hurtin'. And this side, this side is hurtin'. I'm like this all night long.*

Although Sam focuses here on the physical discomfort of sleeping on the street, others I spoke with also talked about the difficulty of ever feeling safe and secure enough to really rest, or told me stories about experiences of being beaten and robbed while sleeping. In such situations, a kind of constant vigilance is required for survival, and this means that these patients battle unremitting exhaustion.

It also means that their temporal existence is structured not around a linear series of events and projections into the future, but around moment to moment survival in uncertain circumstances, an aspect of everyday life that is not usually considered when patients are advised to simply "stop drinking." For Sam, the other temporally defining aspect of everyday life is his life-shattering bus accident, which assumes a primacy that renders less meaningful events almost invisible. For example, when I ask Sam how many times he has been to the ED, he tells me about coming in with a cracked pelvis after the bus accident eight years ago. I ask him when he came to the ED last, and the following exchange ensues:

> *Sam: Eight years ago or something.*
> *Int: Years ago?*
> *Sam: Eight years ago, you know, when I had the cracked pelvis.*
> *Int: That--when you had the cracked pelvis was the last time?*
> *Sam: Yeah.*
> *Int.: So that's been quite a little while then, it sounds like.*
> *Sam: About eight years.*
> *Int: So, I wonder why the nurse thought that you came in--or, didn't you--I thought you told me you'd been here quite a number of times.*
> *Sam: I have. But nothing serious.*

Is Sam being evasive? I don't think so. Instead, I believe this exchange reveals how, for Sam, many of his ED visits (more than 30 in the previous year) simply do not show up for him as emergency visits at all. What "counts" as a visit to the ED is the "true" emergency of the bus accident; the other visits, somehow, are rendered insignificant. The ED is very much in the background for Sam, as for many of these patients: a taken-for-granted aspect of day-to-day reality, but vital to survival, the place where rescue is still valued and rest is sometimes possible.

Sam lives out a version of arrested time, in which, as Merleau-Ponty suggested,

> one present among all presents...acquires an exceptional value; it displaces the others and deprives them of their value as authentic presents...New perceptions, new emotions even, replace the old ones, but this process of renewal touches only the content of our experience and not its structure. Impersonal time continues its course, but personal time is arrested (1994, p. 83).

In this way, Sam's bus accident is not truly part of the past for him; instead, it is part of his immediate, everyday existence in that he must cope constantly with pain and disability from that event. This critical moment has become the atmosphere in which he lives. He expresses no regrets, resentment, or longing for another time or a former way of life. Nor does he talk of a time when, in the future, things might be different. Taking things day by day, one always has this day at least, and disappointments are minimized. In this constricted way, perhaps, Sam "lives forever," as he suggests in a conversation that begins with a discussion of his sailing days.

> *Sam: I traveled, I did my share. I don't care right now. I don't. I make like uh, mileage in life...*
> *Int: So it sounds like you're kinda taking it day by day here.*
> *Sam: Oh, yeah. The way I look at life--heck with it. I don't care if I don't see tomorrow. 'Course I'd like to. (laughs)*
> *Int: Yeah. You'd just as soon.*
> *Sam: Oh, yeah. But that way I'll live forever.*
> *Int: Then what?*
> *Sam: Then that way I will live forever.*

This seems to be a kind of formula for Sam; the way to live forever is to not have too many plans or expectations about tomorrow and not to indulge in regrets about the past. When I ask Sam to explain what he means by "living forever," he gives me an example of a longshoreman friend who was only 42 when he dropped dead, then segues into a peripherally related discussion of living in the longshoreman's hall. There is almost a hint of bargaining, as though Sam hopes that if he can just be satisfied with just being alive, he may be permitted to live longer. Having been granted a reprieve from death thus shapes his life. The cryptic message seems to be that life is short and not in our control, that the way to live forever is to live in this moment, eschewing attachments to both the past and the future.

In the circumstances in which Sam lives, it can be dangerous to project oneself out toward an imagined future; not only is there the possibility of failed hopes further reinforcing feelings of failure and despair, but such effortful striving may distract from the business of mere survival. Likewise, ruminating about the past may drag one down. Sam refers more than once to a girlfriend who brought him vodka to help kill the pain when he was recovering after the bus accident. I ask him if he is still with this girlfriend. No, he replies, with no visible emotion; she died.

> *Int: Oh, really, I'm sorry.*
> *Sam: She died in a doorway. Yeah.*
> *Int: Were you with her?*
> *Sam: No....I got her a room downtown for a few months. Then she died here.*
> *Int: What did she die of?*
> *Sam: I think cirrhosis.*
> *Int: Oh, really? She was a drinker.*
> *Sam: Oh, yeah. (pause). I'm okay. I mean uh, all these drunks, they drink and drink and don't eat. That's what does it.*
> *Int: Not eating.*
> *Sam: And you wind up with a leaking liver, or cirrhosis, or yellow jaundice--you know.*
> *Int: Mhm. How old was she?*
> *Sam: I think about 57, something like that.*

> *Int: Mhm. Not very old.*
> *Sam:...Mm, that's all in the past, you know. That's the way I look at it.*

Sam offers a narrow, spare description of this painful event, as if to tuck it away somewhere and be done with it, keep it from intruding into the present, where he has enough pain already. His girlfriend, important enough to mention several times during the interview in relationship to his care after the accident, is characterized here as one of "all these drunks," a category of otherness in which Sam does not include himself, even though he drinks every day. This enables him to distance himself from both the pain of losing a companion and the fear that he might be prey to the same fate, using a strategy very like that of the ED care providers who view patients like Sam as wholly other.

The fact that Sam says first "she died in a doorway" and later says "she died here" suggests that someone--perhaps Sam himself --found her in a doorway and had her brought to the ED, where she could not be saved. The girlfriend shows up in Sam's story as, perhaps, hopeful evidence of his own comparative health and as moral lesson, not as lost person and friend.

The man who runs a local liquor store is a key support in Sam's life. Sam first brings this up when I ask him where he usually eats, and he tells me that he goes to "Joe's."

> *Sam: It's a little liquor store I know and they always feed me.*

Sam has been patronizing this liquor store for many years. When Joe took over, about fifteen years ago, the prior owner introduced Sam to him as "one of your best customers," and Joe runs a tab for Sam which he pays at the end of every month. Throughout the course of the interview, Sam reveals that Joe is

> *really good to me. My, my check goes direct to the bank. I owe so much to Joe's each month. Why, Joe has given me a lot of stuff...You know, 'I can't sell that here. Take it.' And he could sell this. 'No, here, you take it.*

> *Just don't let me see it.' I mean, stuff like uh, fruit, and vegetables, and, you know. And he could sell this. 'No, I can't. Take it'.*

Joe shows up in Sam's narratives as brusquely generous, a tough businessman who recruits Sam to spy on the competition but has a hidden heart of gold, a secret softness he reveals by looking out for Sam in many ways. For example, when I comment on the quality of Sam's sturdy boots, he tells me that he got them from Joe for only $10. In turn, Joe has Sam's loyalty and regular patronage, but one senses that the relationship has grown to encompass more than mere economic exchange. For example, Joe encourages Sam's own hidden tenderness and care to be revealed toward less fortunate creatures, as the following discussion uncovered:

> *Int: So, do you have lunch at Joe's too?*
> *Sam: Occasionally, yeah. I don't go to [free food missions] or anything else. I mean, it's too much of a nuisance to have to stand in line. I can't stand in line, you know.*
> *Int: Yeah. Because of your legs.*
> *Sam: Yeah, it's--well, this leg here is killin' me. I mean, they're black and blue.*
> *Int: So then what do you do in the afternoon?*
> *Sam: I usually rest around the park.*
> *Int: Rest around the park? Mhm.*
> *Sam. Yeah. Either you sleep, or--play with the damn birds. Nice--at the park, there's pigeons, that come around? And every afternoon, me and my friend would go out there and say: 'Hey, where's Wounded Beak? Where's Wounded Beak? Where's One Foot?'*
> *Int: So there are certain ones you know.*
> *Sam: Oh, yeah. One where he's got uh, one foot, he hops on one. Well, you get by the best you can.*

Sam identifies with and feels compassion for the birds, but it is Joe who gives Sam the bread to feed them, permitting Sam the rare luxury and power of being the giver of help to others. Like One Foot, Sam accepts his trials and blessings with equanimity. He makes a practice of having no particular expectations and not being seduced by desire. He cultivates a posture of independence, and yet he is reminded daily of the limits of that stance. Cultural constructions that pathologize "dependency" flatten out the kind of rich relationship Sam shares with Joe.

There is a sort of raw faith--or desperate determination-- at work in Sam; there is a sense that if he lives right, and is grateful for what he has, he will be taken care of. His frequent homilies ("you get by the best you can") are talismans that help him sustain this belief, even in the face of misfortune. Somehow his integrity is preserved by this unstriving stance.

This faith/determination is challenged and shaken by experiences that remind Sam of his vulnerability and helplessness. He describes renting a cheap room for the night and "trashing it" after it was found wanting. On one occasion, the room has no hot water. Sam believes they were just trying to save money. Another time, he locked his coat in the room and returned to find it gone.

> *Sam: They always say, 'oh, uh, he can get uh, low rent housing.' I don't like that. Those are lousy neighborhoods. And a lousy dump. I went to one of em one time. And it was a warm day. And I left my coat in my room, and when I come back the damn thing was gone. And I locked the door when I went out.*
> *Int: In your own room, you left your coat?*
> *Sam: Yeah. I locked the door. Oh, man, I trashed that damn room before I left. I was really mad. I mean, uh, you pay for a room, you expect something to be there when you get back. And it wasn't. (pause) That's why I trashed that damn room. And they wonder why things like that happen. There's a motive behind everything.*

One senses that Sam is partly angry at himself in this situation. He has allowed himself to have expectations, has been seduced by the keen hope for a warm shower or a safe place on a cold night, and those expectations have been dashed, reminding him of the vulnerability he works so hard to forget and rents a room to temporarily escape. In alluding to the anonymous owners who "wonder why things like that happen," Sam invites

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us to share his moral outrage and its natural result, which he feels is justified in the circumstances. He feels "trashed" in this situation and he "trashes" back. His actions are a way to feel some sense of power in a situation where he feels powerless. Sam's rage is a defense against helplessness and dependency, but it is also the entirely rational response of a "customer" who knows that his complaints will go unheeded in a situation winked at and tolerated by authorities.

Like almost all the patients I interviewed, Sam has only positive things to say about the emergency department and the people who work there. When he has to wait a long time, he says, "that's natural," because there are others with more serious problems. He resents some patients whom he characterizes as "fakers," who come just to get a place off the streets and rest for awhile, even though he admits elsewhere in our conversation that he would really like to get a shower and he needs a good rest. His ethic is grounded in notions of self-sufficiency and authenticity. Unlike many of the patients I spoke with, however, Sam does not see himself as "known" by the ED staff, even though the nurse calls him by name and they laugh together in a familiar way over his habit of falling asleep on the bench outside while waiting and having to re-register because he didn't respond when they called him.

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> *Int: Do you go to other hospitals? Do you go to other emergency rooms?*
> *Sam: Naw. This is the only one where I know I'll get the best of care.*
> *Int: Oh, really? You come here because you feel like the care is better?*
> *Sam: Oh, yeah. Might be uh, a longer wait, and all that, but uh, oh, the care is good.*

He also notes that

> *All I can say is, they serve me good here when they get, when they get around to me. There's a lot of other people that come in, more serious than me. They gotta look after those first, right?*

This concern with those who are worse off was a repeated refrain among many of the patients I interviewed. There is a kind of comfort and protection in knowing--even visually seeing--that awful as one's own plight may be, others are faced with problems even more severe. The emergency room thus serves as a place in which one's problems are put in perspective; it is public proof that one is not entirely isolated in suffering, but shares that with others as part of the human condition.

In addition, the delay involved in waiting and watching those with more serious problems be cared for is usually not considered an irritation by these patients. For Sam, the longer the wait, the longer he gets to rest in a warm, safe place.

> *Sam: I wonder what the heck they can do, you know? I need, I need a few days' rest.*
> *Int: How do you do that, when you're out on the street like that?*
> *Sam: Need a park bench.*
> *Int: Yeah.*
> *Sam: 'N' that gets rough.*

A review of Sam's medical record reveals that out of 35 visits in a one year period he "left without being seen" 23 times; the common interpretation of this phenomenon is that patients grew tired of waiting and gave up or went elsewhere for care. However, as I came to understand only through talking with these patients, it often actually meant that they went quietly to sleep sitting upright in the waiting room or lying on benches outside and, exhausted, did not respond when their name was called. I ask Sam how he could sleep in the waiting room, since the television always seemed to be blaring at an intolerable volume. "I just close my ears to it, you know," Sam responds, comparing it to the noise of the engines on the ships he worked on.

The medical record also reveals repeated discharge instructions to "stop drinking alcohol," but these instructions seem almost a rote admonishment, not a realistic remedy. Alcohol figures heavily in Sam's pain control strategies, but I saw no evidence in the

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medical record that this aspect of his drinking was addressed, either by discussing its effectiveness or prescribing alternative pain control measures, despite the fact that Sam had repeated visits for chronic venous insufficiency, leg pain, and cellulitis. Alcohol also is central to his relationship with Joe and with other people he knows around the park.

> *Sam: I remember with Frankie, he was about 42. He was a longshoreman. He'd always be around the hall, he'd say, 'Want a drink? Want a drink? Want a drink?' I'd go, 'yeah, yeah, yeah,' you know, 'Bring me a vodka.' -- That damn fool, he would drink, he wouldn't eat. And one day I go to the union hall; the vice president says, 'Hey! Hold it there, Sam.' 'What do you mean?' 'I just found Frankie dead back there.' That was from drinkin' and not eating. Now, your body's got to get so much--it's bad enough I abuse it with alcohol. He died of malnutrition.*

Sam's favorite drink is Country Club Malt Liquor Olde English 800, he tells me. I ask why that brand, and he explains:

> *Sam: I like Olde English 800 'cause it's sorta filling, and--nourishing, you know. You know, like Budweiser, I don't like those.*
> *Int: You think it's more nourishing than other--other alcohol.*
> *Sam: I think so. I could be mistaken, but--*
> *Int: Why do you think that?*
> *Sam: Hell, I been drinkin' that for about the past--maybe ten, fifteen, the past 20 years.*

Sam interprets the drinking as a stressor on his body, but because he understands nutrition as critical he chooses a particular type of drink; this belies the common perception that such patients are not even trying to take care of themselves. On the contrary, at least to some degree, Sam interprets his drinking *as* taking care of himself inasmuch as it relieves his pain and provides nutritional benefit to help offset what he knows can be its ill effects on his body.

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Sam's medical record reveals other discharge instructions that, given his situation, seem unrealistic. These include "stay off foot as much as possible," "keep leg elevated," "avoid direct sun on hands," and "wet to dry dressings twice a day." The practical realities of carrying out these instructions involve resources Sam simply does not have: pillows or chairs to elevate his foot; gloves to protect his hands; money to buy dressings and saline and a place to undress and change his dressings. The instructions he is given reveal how thoroughly context is excluded and how absurdly anachronistic "care" becomes when patients are viewed only as their medical problem.

Sam does not seem to interpret this failure critically, however. While most of us might understand caring in a more positive, active and morally personal sense, in Sam's world caring can mean simply being allowed to be in a place without being threatened in some way.

> *Sam: See, where I stay..._____Park? Every darn cop out there knows me. ...I can be sittin' there with a drink right in front of me. I see 'em comin', I go like this with it (puts hand inside coat). They see me go like that. I know those guys.*
> *Int: They don't do anything?*
> *Sam: Naw. Only thing they bother if, uh, I'd be a violent drunk or something...Or if you annoy the crowd, or anything, you know, the tourists. I'll be sittin' there like this--'Oh, here comes one,' (puts hand inside coat again) and you know, they don't bother me.*
> *Int: They don't bother you.*
> *Sam: No. And they're good to me.*
> *Int: The cops are good to you?*
> *Sam: Oh, yeah.*
> *Int: What do they do, how are they good to you?*
> *Sam: Well, they don't bother me.*
> *Int: Well, that's bein' good.*

> *Sam: See, one time, this other guy and I were sittin' there drinkin', and I said, 'Oh, I'll get up and buy one now.' I came back and they had him surrounded. (laughs)*
>
> *Int: Oh, really? They didn't know him, I guess, huh?*
>
> *Sam: I don't know. He had a record of violence in the park.*
>
> *Int: He wasn't somebody you knew, then.*
>
> *Sam: Naw, I didn't know him.*

Here the police have protected Sam from a potentially violent person, but in general they are also "good" to him by not bothering him and allowing him to circumvent the rules as long as he does not disturb anyone. The fact that he acknowledges respect for the rules by hiding his bottle when indicated allows him the privileges of familiarity. This is a modest, almost imperceptible but significant form of recognition and thus a kind of public caring (see Chapter Eight). He is "known" in the park and shows up as someone who is trustworthy.

When Sam wants to get cleaned up, he has two options: getting a shower at the ED or going to a moorage where he is "known" from his days of working on boats:

> *Sam: You gotta be a boat owner to get in. Well, they think I own one. Well, they used to see me down there all the time, workin' on this boat and that boat, you know...I go 'I uh, I own this one over here.' They know I'm only kiddin'.*

Again, Sam is recognized by authorities at the moorage as a person whose worth is acknowledged in special privileges. He displays a sense of humor and a stubborn refusal to let his situation defeat him. Even when given the opportunity, Sam refuses to portray himself as victimized, instead recalling the triumph of learning to walk again:

> *Int: What's the roughest time you ever had out there?*
>
> *Sam: I don't know. I had a lotta good times, too. Ow! See in--they go deeper in this side than in that side. (inaudible) I guess I'm gonna have to learn to live with it. Yeah, I remember when I was first operated on. Had*

> *to learn to walk all over again. I did, too. At first it was--crawlin' along on the ground, and that damn therapist--'No! You* walk*!'*
>
> *Int: Really pushed you, huh?*
>
> *Sam: I'm glad she did.*
>
> *Int: Well, you look like you do pretty good, considering.*
>
> *Sam: Oh, I do. I hurt right here, you know. Only thing that gets me is I'm gonna be hurting for the rest of my life. This damn--right leg, it hurts me. 'N' it's gonna hurt me the rest of my life. But at least they made it so I could walk on it. You know. (inaudible) Now it hurts in the toes. And they wonder why I drink so much. But that's no excuse to drink.*

Sam carries on this kind of small conversation with himself about alcohol almost constantly during our talk. The everyday ordeal of coming to terms with unrelieved pain and functional impairment is made a little more bearable by alcohol, yet Sam's stories show his awareness of the price such relief extracts. Death has brushed by him more than once, alcohol always on its chilling breath, yet alcohol has also been his release from suffering. Abandonment to nihilism is tempting; yet Sam has not surrendered himself to alcohol nor to hopelessness. He finds people and things in his life that matter, even as he protects himself by claiming not to care:

> *Sam: You know, like in Santa Barbara, I knew this one old gal. She died; she's oh--I mean, she put it in writing. I was supposed to get everything she had. You know what she left me? A whole mess of unpaid bills. Heh-heh-heh! ...Because the house, that was--had liens and everything...I said, hell, I'm not responsible for those. Believe me, I (inaudible). That's one reason why--I don't care. Well, I do to a certain extent. And I don't care for nothing. I don't say that. I don't know. It's like--I'll get in here and take a shower, then tomorrow I go to Joe's, (inaudible) my clothes up, you know--it's hard to stay clean, you know. Now, see, most of the cops in that park, they know me. They go, "Hey, we seen you on ____Street the other day," and "Sure," and they see me walkin' down the street with Margie...*
>
> *Int: Margie?*

> *Sam: Yeah, a girl I know. "Hey, is that a new girl?" I'm like, "Yes, sir, brand new." Heh-heh-heh!*

Here again a story of past failed expectations is quickly followed by a disclaimer of concern and a refocusing into the immediacy of today. Sam wrestles with the vulnerability of caring; he tells himself not to care in order to spare himself from the pain of further losses, but he is still vigorously engaged in the world. Sam resists indulgence in regrets about the past but will allow himself the luxury of a little hope for the future.

Spare though Sam's world may look to an outsider, its simple pleasures--being recognized, being alive, being among others--are meaningful to him.

> *Sam: Long as I manage to eat, drink, sleep--hell, I'm happy.*
> *Int: The basics, huh?*
> *Sam: Oh, yeah. Basics in life. Even without a drink I'm happy. No kiddin'. It all depends.*

Discussion

The moral demands involved in witnessing the vulnerability of others and confronting our own vulnerability in the process are profound. The coping stances we assume in the face of our helplessness to control it all can extend the vulnerability of others by rendering them wholly other, isolating them further from the human community. ED care providers, as society's "rescuers," are faced with the impossible task of trying to cover over, on behalf of society, our finitude, our common embodiment, and the utter contingency of our everyday lives. They are also faced with trying to cover over the inadequacies of a system that renders basic human needs for care invisible or illegitimate. Heavy users of emergency services, inasmuch as their status as "unfixables" and their prolonged public deterioration interferes with these tasks, force providers to face up to the limits of medical heroism and the limits of medical progress, technologically conceived.

There is, after all, something peculiar about living in an increasingly fearful society in which people require labels on ladders, warning of the risks if one should climb up on them and fall off, yet seek out experiences like horror movies and bungee jumping, through which they can experience the thrill of being terrified. We have become culturally comfortable, no longer threatened daily by the fear of wild beasts or a capricious and powerful nature. Death is "tamed" by our technology (Aries, 1981; Arney & Bergen, 1984). But not really.

The "real as it gets" aspect of the ED allows providers to peek into this cultural secret, to look behind the curtain they are expected to draw over the taboos of disability, dependency, and death. In this cultural space we have the perfect hindsight in which it is possible to imagine we know precisely how the terrible events of life could have been prevented from happening, and our heroic activities of rescue can convince us, for example, that in restoring a heartbeat we have faced and conquered death. But the curtain is not thick enough; the illusion cannot hold.

CHAPTER EIGHT

RECOGNITION

Jack: Emergency I pretty well conquered after ten years. (laughs) Conquered. Actually, what it is, the ones that got so sick of me either died of old age or some immoral disease, or they started to like me. One or the other. But either way, they're not here, or they're here and they're dedicated in a true, honest-to-God, 9 to 5 my ass; they're just human beings. And they still have their faults just like I do...But, you know, they somehow have got over ten years in the system, and they're either mentally deranged themselves—which is usually what it is—they identify with me (laughs)—or they realize that I'm not such a bad guy, even though I either don't say anything or I say too much. But they know I'm real. And that's what hurts them. They know I'm God damn real and other people like me that we're here and there's nothing you can do other than get a lobotomy to get [us] out of [your] mind.

Clerk: Well, Marjorie came in about two or three months ago. And started crying on her way out because I was the only one left that she knew here. And she was crying. And she said, 'I don't like coming here any more because there's nobody left, you know, that I know.'
Nurse: Yeah, I ran into her, same situation. She was in a couple of weeks ago. And her big spiel was 'Jesus Christ', you know, 'the old nurses'—thank you, Marjorie—'know how to take care of patients. These young punks, you know, they don't know anything' and, you know, just totally furious at this younger generation of people who don't know who she is. I mean you, you treat her differently. You put up with a certain amount of crap from her that you wouldn't with just anybody that came by, because, you know, or there's a part of you that, I mean, she's like family. And—you know, even though you wouldn't want her in your house! She's like family, and it's like—and you cut her some slack.

Recognition

Recognition as Central to Human Existence

Recognition, according to Jessica Benjamin, "is so central to human existence as to often escape notice; or, rather, it appears to us in so many guises that it is seldom grasped as one overarching concept" (1988, p. 15). Recognition by others, the way others allow us to show up *as* ourselves (Heidegger, 1962), is basic to our existence as human beings who take up our lives as situated in relation to others, yet we seldom consider its importance in importance in our lives. As discussed in Chapter Three, recognition is central to selfhood, and when attempts to seek such recognition falter or fail, identity is called into question.

Recognition, as the term is used here, means something more than perception of someone or something previously known. Benjamin writes that "recognition is that response from the other which makes meaningful the feelings, intentions, and actions of the self " (1988, p. 12). According to Benjamin's important and well-argued thesis, there is a necessary tension between self-assertion and mutual recognition that allows both self and other to meet as fully human equals. It is when this balance breaks down that relationships degenerate into domination. Recognition makes self-assertion possible and self-assertion sets up the possibility of recognition.

Recognition practices are thus central to caring practices, as Benner (1994b) has pointed out, and involve connection, mutuality, and involvement with particular people in particular situations. To recognize and be recognized by someone is to place oneself *with* another within a meaningful frame of activities, shared understandings, and possibilities. It is not possible to care for another without recognizing them *as* at once uniquely and commonly human; further, the kind of recognition we experience both sets up what kinds of caring are possible in the situation and figures in how we understand our own possibilities.

For example, when patients and providers acknowledge one another only in terms of power relationships, as in the adversarial situations described in Chapter Six and Chapter Seven, caring practices are degraded to mere procedures and the relationship shows up as a transaction between user and used. In such a context, providers experience themselves as overworked technicians and their patients as obdurate objects. Patients, in turn, are forced to resort to manipulation and medicalizing "tricks" in order to obtain the symbolic but unsatisfying "care" of a bag lunch grudgingly given. Both experience themselves as morally violated.

Instrumental Rationality

Taylor (1991) describes this way of relating as a result of the primacy of instrumental reason in our culture. Instrumental reason, according to Taylor, is

> the kind of rationality we draw on when we calculate the most economical application of means to a given end. Maximum efficiency, the best cost-output ratio, is its measure of success (p. 5).

The instrumental stance restricts possibilities for both patients and providers and minimizes opportunities for growth and transformation. Means eclipse worthy ends, and the moral sources for action are disregarded. In contrast, when providers and patients are able to recognize one another as mutually vulnerable, embodied, and finite, and when other values besides efficiency are acknowledged as worthy, they begin from a position of shared humanity that allows for the possibility of transcending stereotypes and yet acknowledging difference.

Disordered Recognition

The patient participants in my study often revealed what I might call disorders of recognition, insofar as their relationships with significant others were absent or disturbed and their constrained social and economic circumstances severely limited their opportunities for meaningful self-assertion. I want to consider, in this chapter, the notion that a visit to the ED is for many of these patients a form of self-assertion and a plea for recognition. But providers also revealed issues related to recognition. When caring practices are viewed strictly from the standpoint of instrumental reason, as I found they increasingly are, providers can only show up as mere technicians, feeling inauthentic and sometimes cruel, not as humans engaged in socially and personally meaningful, necessary work. This chapter will discuss the significance of recognition, the recognition practices engaged in by both patients and providers, and the ways in which these practices are preserved or impeded.

The Risk of Recognition

As noted in Chapter Five, a majority of the patients whom I interviewed lived in marginal economic circumstances, and a number of them were homeless or intermittently so. Such patients, I learned, tend to cultivate a persona of obscurity in order to survive in the brutal world of the streets. In such a world, being "known" too well by others sets one up to be taken advantage of, physically, economically, or emotionally: in short, to be "known" may be to risk one's self.

In addition, alcohol or drug use may dull the ability to make good judgements about others' trustworthiness or the relative safety of a situation; thus people whose lives are essentially organized around their substance use tend to limit intimacy as a way to protect themselves from further hurt. Such a posture also helps them hide from and temporarily forget their problem, since the few others surrounding them often have similar substance use problems and are less likely to confront them about changing their behavior. This guarded stance can become habitual.

This helps us to understand, perhaps, why some of these "heavy user" ED patients are "noncompliant" in making clinic appointments or maintaining a relationship with a primary care provider. Yet being "known" is essential to having an identity. This puts individuals such as many of those whom I interviewed in another "double-bind" situation in regard to the self: self-assertion may be dangerous, yet without it there is no recognition from others and thus one's boundaries may become increasingly indistinct, further decreasing the possibility of meaningful self-assertion. Under such conditions, maintaining a coherent narrative construction of the self (Giddens, 1991) is made more difficult. For patients with chronic mental illness, who may already have difficulty establishing safe boundaries for themselves, life on the street risks disintegration of the self.

Paradigm Case: Buddy

Int: How long have you been waiting here?
Buddy: I don't know. I don't remember comin' in here.
Int: You lost track of time.
Buddy: Right. I blacked out again; I'm dimmed out.

Buddy, a 74-year-old man, is lying on a gurney near the triage desk. The triage nurse says Buddy comes in all the time: "ETOH [alcohol], noncompliant with his meds, comes in to rest here." Buddy is overweight but appears oddly small, swathed in several cotton flannel shirts. He lies carefully on his back under his narrow-folded blanket and is very grateful that the nurse brought it to him. He has a childlike air about him; his conversation comes in short sentences, little gusts of words.

Buddy says he is a veteran of World War II and the Korean War; his talk is spiked with ruminations about "dead bodies" and people dying in the war. "I'm just screwed up," Buddy says, when I ask him to tell me about what's going on with him now. Like most of the patients I interviewed, Buddy lives on about $600 a month; he gets checks from Social Security and the Veterans Administration (VA). He has seen a VA psychiatrist in the past for anxiety. Right now he has a hotel room for a few days, arranged by the social worker at this hospital, but in another day or so he has to move on; he says they won't let him stay longer than 3 days. He last had a regular place to live about six years ago, a room for about $50 a week, but, he says, they "threw me out of there for drinking."

Asked what brings him to the ED this night, he answers,

Buddy: Well, my feet are very heavy. I don't know what's wrong with my feet. I think I got gangrene in one toe.
Int: What do you think they're going to do for you here?
Buddy: I don't know. I, I have noplace else to go.

Buddy is perhaps the most isolated among those I interviewed. He says his parents are both long dead and he had two sisters, but

> *Buddy: I haven't seen them in a looong time.*
> *Int: Where are they?*
> *Buddy: I don't know what happened to 'em. They got married. I don't even know what their names are now.*

This complete loss of any family ties suggests a disconnection more profound than that of many of my other participants, who manage to maintain some kind of knowledge of or relationship with family, even if that relationship is estranged or dysfunctional. He never married or had any children, Buddy says, and he is alone now.

> *Buddy: They're all gone, I mean, uh, and I don't have anybody left now. Except Jody. Uh, now, uh, I've got her. Uh, she's a black lady, but she's a very good person. Uh, I seem to be attracted to her for some reason; I--she reminds me of my mother, I think.*

Jody, he tells me, stays at a hotel in a nearby city; he has stayed with her and panhandled with her, but it is strictly a platonic relationship, he is careful to assure me. According to Buddy, Jody was badly beaten by someone--he doesn't know who and she won't tell him -- who disfigured her face; he ruminates hazily about this as he does about war. Later in the conversation, he confesses that he isn't interested in sex and thinks of Jody as his mother; still later, after saying that "if you have somebody to take care of you, you're all right," he confides that

> *Buddy: It wasn't my idea. It wasn't my idea. But she split up with me. And, uh, oh, I'm a lot older than she is, too, you know. See, I'm over 70 now. 74. And uh, I don't know what happened. But uh, she never--this was her idea, not mine.*
> *Int: She went her way, huh?*

Buddy: I uh, would like to be with her. (pause) I think she's got another boyfriend, too. Yeah, I really think she does. Well, uuh, —see, I never went for that stuff. Sex. I, I, I don't go for that at all. I'm, uh, (pause) I look on her as my mother.
Int: It's a different kind of relationship.
Buddy: Different, oh, yes. And uh, I never—that was never my idea of fun. Sex. I never—gave that any thought.
Int: What is your idea of fun?
Buddy: Drinking. (small laugh) Just drinking.

Jody is a drinker, too, and that is why she panhandles sometimes. Buddy says panhandling is "belittling," and that he doesn't "care for it," but he has done it sometimes with Jody, in order to get more money to drink. While Buddy continues to think of himself as Jody's "boyfriend," this relationship, like those he may have once had with his family, seems lost, even unreal. Buddy himself seems insubstantial, almost translucent, a bottomless pool of naked needs. It becomes discomforting to be around him, after a bit; I found myself feeling a vague anxiety over continuing the interview too long, as though I might not be able to find a way to end it. Yet it would be almost impossible to like or dislike him very strongly; there was almost no one there to have feelings about.

Buddy doesn't remember how he got here; in fact, the last thing he remembers is drinking with an acquaintance this morning and then being robbed as he went into a store to buy more liquor. He is at first not sure what hospital this is and thinks he is in another county.

I ask Buddy to tell me about his day.

Buddy: Oh, God, I was talking to this guy from Canada. We're having a nice conversation. I gave him a few drinks. I met him over downtown.
Int: Somebody you didn't know before.
Buddy: I didn't never met him before, no, but he's a nice fellow, and uh—
Int: Were you in a bar, or—

Buddy: No, on the street, we were standing on the sidewalk. And then I went in just to get a few more drinks, get a drink, and that's when I got robbed. And uh, right in the store. The guy come in and grabbed the money from my hand.

Int: The same guy you'd been talking to?

Buddy: Oh, no. Oh, no, no. This is a different person. Different, yeah. Oh, and uh, I don't know what happened after that. I blacked out again.

Int: Did he hit you on the head?

Buddy: Oh, no, he just grabbed the money from my hand.

Int: And you say that's happened to you before, that you've gotten robbed?

Buddy: Oh, I've been robbed before, oh, yeah. I've been mugged before. Oh, yeah, they followed me into the doorways and all that stuff. That's happened. But I've never been beaten up, though. They just grab the money from me. I don't recall being beaten up.

Int: So then what did you do after that today?

Buddy: I don't know. I blacked out again. I dimmed out and I don't know what happened.

Int: And then what's the next thing you remember?

Buddy: Just waking up here.

Int: Oh, really, so you, you've got some blank spaces in there, it seems like.

Buddy: I do, yes. I got, I got blank spaces.

Int: Is that hard?

Buddy: Yeah, it's kind of--well, it erases the memories of everything but uh, it's hard, you know.

Int: You have bad memories?

Buddy: All those guys that died during the war. Oh, man, I keep thinkin' about them all the time.

Buddy tells about being robbed without any visible emotion. There is no anger at the injustice, there is no fear at what might have happened, and there seems to be no particular moral lesson in the story. It is told matter-of-factly, almost woodenly. For Buddy, nothing stands out as more or less important, except drinking. Even his statements about the war, which recur over and over, are flat and nonspecific, made almost in an habitual way. There is no attached narrative to flesh out the concern, no story. The closest he comes to displaying what sounds like something that could be interpreted as agency is when he says, near the conclusion of the interview, "frankly, I want to go down and get another drink."

Buddy likes this hospital and another public hospital because the social worker found him a place to stay and because

> *Buddy: They leave you alone. They don't bother you much; they don't harass you. In, ah, they're pretty good places. Like in some places they harass you.*

When I ask him about this, Buddy shares a story about being taken by ambulance to a private hospital, where the ED physician became angry with him for coming in too often.

> *Buddy: He, he came and told me. He says, if you come in again, I'm going to write a letter to Medicare. Well, I, I'll try not to go there if I can help it. I just won't go there.*

This is the closest Buddy gets to telling a real story at any point in the interview. Later in our conversation, he brings up the subject again:

> *Buddy: The doctor, he got annoyed 'cause I was comin' in so much. I was --I don't know. I, I, I've called for the medics, and the Army taught me how to do that. Call for the medics. And ah, they'd take me there. You know, it --they're always--*
>
> *Int: Do you request to go to that hospital, or do you make a request as to where you want to go?*
>
> *Buddy: I didn't request it. They--I was in that area, I guess.*

Buddy gives an impression of being almost entirely passive. He just "was" in the area; there is no sense that he got himself there or chose to go there. Like human flotsam, Buddy washes up haplessly on the shores of various emergency departments through no particular effort of his own, except perhaps sometimes "calling the medics." He feels vaguely wronged by the doctor's anger, but only vaguely; he was just doing as he had been taught, calling the medics when he needed help, and otherwise trying to stay as invisible as possible.

As they are for Sam (see Chapter Seven), emergency departments are "good places" to Buddy if he is not "harassed" there. However, Sam's narratives revealed the existence of intact relationships with people who cared about him; Buddy seems to have only Jody, and that relationship seems insubstantial at best. Goodness, for Buddy, is definable as an absence of badness. For example, Buddy makes frequent references to "trying to be a good person" or Jody being "a good person." Yet he never indicates what being a "good person" would look like; this phrase, like his war references, is used almost in an habitual way. The way Buddy links harm with goodness suggests that being "good" may or should mean that bad things don't happen to you.

> *Int: Well, just tell me a little bit about yourself first, because I don't really know you at all.*
> *Buddy: I know, but, well, I try to be a good person if I can. I got robbed last night again.*

Later, talking about Jody, he uses this phrase again and follows it rapidly with another sentence about being harmed.

> *Buddy: She drinks, yeah. She's a good person, though, a very nice person. I, I feel sorry for her because somebody hit her like that. They hit her terrible. They disfigured her face. That bothers me all the time. I think about that.*

In Buddy's very elemental moral universe, goodness is a rather nebulous undeservedness of harm or absence of harm, rather than something actively revealed through one's good works. Goodness has no positive character; he neither talks about generating it nor describes its dimensions.

Likewise, badness has little specificity when it appears in Buddy's talk, and he does not see himself as able to avert badness. The issue of safety was paramount for many of the participants I spoke with, many of whom had well-developed practices for trying to ensure their own safety. In contrast, for Buddy, harm just happens, and he entertains no notions of being capable of deterring it.

> *Int: When you are on the street, do you go to shelters, or where do you sleep?*
> *Buddy: Well, you got to hang out the best way you can. Uh, sometimes you just have to sleep on a bench. That's about the only way to do it.*
> *Int: Like a park bench or what kind of bench?*
> *Buddy: Park or just a bus stop or some place. Just go to sleep there.*
> *Int: I mean, do you have any particular places that you tend to go if you're out like that?*
> *Buddy: No, I, I just, where I'm at, like the bus station, or even—*
> *Int: Is that safe?*
> *Buddy: Well, it's not always safe, I'll tell you that. You got to be careful—*
> *Int: How can you be careful when you're sleeping?*
> *Buddy: —that they'll rob you. (chuckles, apparently in response to my question)*
> *Int: Do you sleep with one eye open?*
> *Buddy: Well, that's the trouble. No, you can't do that. You just get robbed.*
> *Int: Well, that puts you in kind of a tough spot 'cause you got to sleep sometime, don't you?*
> *Buddy: Oh, God, yes.*

Perpetually exhausted by anxiety and lack of safe sleep, Buddy wanders in a dangerous terrain apparently devoid of particular, meaningful familiar places; he ends up where he ends up, again through no particular efforts of his own. Buddy's whole life is an emergency. He is disconnected from any personal geography or history, adrift in a world in which undefinable, unpredictable, and unavoidable harm is always present.

Discussing a skid row area he has frequented in the past, Buddy remarks that

Buddy: You never know who you're gonna run into at night. So you have to be careful.
Int: So how do you be careful?
Buddy: Well, you got to watch your step, here—. I, I, I was lucky, I never got hit there but you never know what, what might happen.

Like a soldier hurrying from foxhole to foxhole, Buddy lives in a constant state of largely unarticulated anxiety. He is psychologically disfigured, still living in a war situation, facing constant risks which have almost obliterated any meaningful distinctions. The risks Buddy faces come both from within his own tormented psyche and from those who would prey on him in his helplessness. Exhausted by mere survival, he drinks. The drinking, he says, reduces his anxiety.

Buddy: The drinking really does help me.
Int: Oh, really?
Buddy: Yeah, it takes the edge off.

Buddy's world is constituted by it. Drinking is Buddy's way of meeting people and having socialization, however impoverished; his way of being recognized as needing help; his way of having fun; his way of seeking comfort, and his link with his days in the Army, as he reveals when he talks about drinking "boilermakers" (a combination of whiskey and beer) in noncommissioned officers' clubs. I ask him if drinking has ever caused him any health problems, and he answers, rather vaguely:

Buddy: Yeah, I got the DT's once and all that stuff.
Int: Oh, yeah?
Buddy: Oh, yeah. I had those. DT's, yeah. Hallucinations. It causes problems. But it breaks the monotony, anyway. I don't know. So. Oh, we, we had a lot of happy drinkers in the Army.

Here it is difficult to tell whether Buddy is referring to drinking or to having DT's as "breaking the monotony," and I failed to ask him to clarify. Either way, this remark is telling for what it reveals about Buddy's everyday experience, which is unbroken by enduring commitments to either relationships or work.

If to be a self means maintaining a sense of agency and continuity, in which one has a clear sense of possibilities for the future, Buddy reveals an extremely fragile self. When I ask him where he sees himself six months from now, the idea seems to provoke anxiety, and he switches the conversation quickly to a current event which appears far removed from his immediate situation.

> *Int: Well, where do you see yourself six months from now?*
> *Buddy: I don't know. Gosh only knows what's going to happen six months from now; I don't know. I don't even want to think about that. What's going to happen to Haiti?*

Whether from years of drinking, injury, exhaustion or mental illness, Buddy gives the impression of having considerable impairment of short-term memory. As the interview draws to a close, I ask Buddy if there are any questions he'd like to ask me.

> *Buddy: Well, you're a very nice person. You come up and spoke to me like this. I don't know what to say. I, uh, I guess the best thing for me to do is go back downtown.*
> *Int: After they look at your foot, you mean.*
> *Buddy: Uh, haven't they looked at it yet?*
> *Int: No, you're still waiting to be seen. You're just waiting outside the emergency room.*
> *Buddy: Oh.*
> *Int: They just gave you a place to lie down. I guess they must be busy in the back.*
> *Buddy: Oh, I didn't know that.*
> *Int: Yeah, so you're still waiting for the doctors to look at your foot.*
> *Buddy: She, uh, the lady come up, the nurse came up, and gave me this warm blanket, I know that. She was nice to do that. She knows my name.*
> *Int: She does?*

> *Buddy: Oh, yeah.*
> *Int: Do you know her?*
> *Buddy: She called me Buddy. Yeah, I don't remember her, but I, I, apparently I do.*
> *Int: You've seen her before.*
> *Buddy: Yeah, I must have, yes. She knew my name.*

Impaired though he is, however, unable even to remember whether or not he has been seen by the doctor and medically treated, Buddy does remember being treated with kindness by the nurse and called by name. For Buddy, it is significant when someone recognizes him or speaks to him, something to remark upon; living a life of obscurity almost to the point of nonexistence, even such seemingly basic, simple gestures as offering a blanket and knowing his name stand out as important and meaningful. In fact, the "chief complaint" of his foot problem is clearly not of primary importance to him right now, as I discover when he says he wants to leave and go get another drink.

> *Int: Maybe you should stay and get your feet checked first, since the doctors haven't seen your feet.*
> *Buddy: Well, they--they saw 'em the other day.*
> *Int: They did?*
> *Buddy: Yeah, I'm supposed to come back on the 28th.*
> *Int: Oh, you are?*
> *Buddy: Yeah, to be rechecked. But not today. I, I'm supposed to come back at 10 o'clock.*
> *Int: How do you keep track of that if you're out on the street?*
> *Buddy: Well, I have a pretty good memory for things like that, um--they gave me the letter. I remember that. They told me.*

Given that Buddy cannot remember whether he has seen the doctor today or not, it is remarkable that he claims to remember when he was told to return for follow-up; what this conversation really reveals, however, is how *this* ED visit is not now and perhaps was never really about his feet. Instead, it was about finding a safe place to rest for a little while from the exhausting work of subsisting. It was about being recognized, even if only for a moment. It was about being offered a thin blanket, a remnant of human comfort.

> *Buddy: I don't think they can do much for my feet. I, I think I got gangrene in one toe. I have gangrene.*
> *Int: You're gonna have them see about your feet.*
> *Buddy: I have gangrene now I think. It's sore but there's nothin' much they can do about it, I don't think.*
> *Int: So then what are you hoping that they will do?*
> *Buddy: Oh, it's just some place to come to, to get some kind of help, assistance, shelter, or something.*

Meeting the Self

Buddy's story reveals how deprived and sparse an identity remains when connections with others are absent. Even his own body seems peripheral, something he views in an almost disengaged way, as when he remarks upon the likelihood that he has gangrene. Giddens (1991) suggests that a stable self-identity involves biographical continuity which can be communicated to others, a "cocoon" of practical activities that protect the self from dangers, and sufficient self-regard to sustain a sense of agency. A "fractured" self, in contrast, lacks one or more of these crucial characteristics. Drawing on the work of Laing, Giddens suggests that discontinuity in temporal experience is one feature of such persons:

> Time may be comprehended as a series of discrete moments, each of which severs prior experiences from subsequent ones in such a way that no continuous 'narrative' can be sustained. Anxiety about obliteration, of being engulfed, crushed or overwhelmed by externally impinging events, is frequently the correlate of such feelings. Secondly, in an environment full of changes, the person is obsessively preoccupied with apprehension of possible risks to his or her existence, and paralysed in terms of practical action. The individual experiences what Laing calls an 'inner deadness' deriving from an inability to block off impinging dangers--an incapacity to sustain the protective cocoon...People engulfed by such anxieties may seek

> to 'blend with the environment' so as to escape being the target of the dangers which haunt them. Thirdly, the person fails to develop or sustain trust in his own self-integrity. The individual feels morally 'empty'...(1991, pp. 53-54).

Giddens argues that while a stable self-identity presupposes a relationship with others, it is not directly derivable from such relationships. I agree; however, I believe his conception of identity underestimates the importance of recognition from the other to the ability to sustain a coherent narrative about the self--particularly, I believe, in circumstances of danger or transition. I am not suggesting that others can independently construct or sustain one's self-identity, but in situations where one's existence is experienced as continuously imperiled, or where one is attempting to change deeply ingrained patterns of behavior, the recognition of others helps one be a self through mutual participation in construction of the coherent narrative. Through others, one meets the self. Cassell writes that

> There is no self without others, there is no consciousness without a consciousness of others, no speaker without a hearer, no dreamer who does not dream in relation to others, no act or object that does not somehow encompass others. There is no behavior that is not, was not, or will not be involved with others, even if only in memory or reverie. The degree to which human interactions are literally physically synchronized is amazing. Take away others, remove sight or hearing, let the ability to synchronize activities be injured, and the person begins to be diminished (1991, p. 40).

Buddy reveals almost no sense of agency, has no coherent narrative, and seems, like the "fractured" self of which Giddens writes, to occupy a temporally unanchored space. Buddy's time in the Army may have provided him, for a time, with the structure his life now lacks; it would at least have assured him of food, shelter, and supervision. Although he did not confirm this, my clinical experience leads me to suspect that following his time in the service Buddy may have been institutionalized in mental hospitals for periods of his life, and he may be among the last of those who were "deinstitutionalized" or otherwise displaced from long-term care situations during the cost-cutting days of the Reagan era.

This policy decision, according to many of the providers with whom I spoke, has clearly contributed to the "problem" of heavy users of emergency services. Nurses described a number of "frequent flyers" who were formerly cared for in state psychiatric facilities and are now either on the street or otherwise trying to survive in situations that do not meet their needs. "Harry" was one of these:

> *Nurse #1: He'd come--he comes in and he stands in--usually--he's a psych patient most of the time. And he'll stand in front of me at the desk and urinate and wet his pants while he's talking to me.*
> *Nurse #2: Oh, Harry does not do that.*
> *Nurse #1: He most certainly did!*
> *Nurse #2: Oh, Harry's continent. I know Harry. I took care of him in (state mental hospital, now closed) a few years ago.*
> *Nurse #1: He stood right there the last time he was here--*
> *Nurse #2: Maybe he was really sick that night.*
> *Nurse #1: --and wet his pants!*
> *Nurse #2: Harry --Harry is a cute character; he suffers from bipolar disease. And he's been to every hospital. And he comes in and goes (imitates Harry) '(static noise!) Code Three! Nine eight five oh three. Stabbing. (Static noise!) Code Three!'*
> Nurse #1: *And he always tells you he--they locked him out of his foster home, or wherever he stays.*
> *Nurse #2: He lives in a group home.*
> *Nurse #1: And uh, he's always saying--and he always comes in usually at the same time at night. 11:30, midnight. And it's always the same story.*
> *Nurse #2: And he's really a cute character. He, he, he plays--he wants to go back to an institutionalized life in the psych facilities. And now that they're closing down [state mental hospital], he doesn't know where his home is; that's what his home address is, you ask him where he lives, and he gives you the address to [state mental hospital].*

> *Int: So it's not there anymore?*
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> *Nurse #2: Well, the state's closing it down due to [cost cutting measure].*
>
> *Int: So what's going to happen to him?*
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> *Nurse #2: Well, they're trying to keep him into a group home. But he, he doesn't tolerate it well. His brain just doesn't work. So he keeps coming back and saying, 'I'm going to hurt myself, I'm going to kill myself.'*
>
> *Int: To try to get himself back into a bigger institutionalized--*
>
> *Nurse #2: Yeah. And so one night he came in and we said, 'Okay, Harry, you need to go back to your group home. You're not going to stay here.' 'Well, they won't let me back in.' We called them up and said, 'you've got to accept him back in--this is bullshit.' They said okay, so we gave him a bus pass, and said, 'Go get the bus, you're out of here.' He said, 'You're not going to take care of me?' I said, 'No more; you're taken care of; you're gonna go back to your group home.' 'So what if my wrists were cut?' I said, 'then we'd take care of your wrists and then we'd send you to the group home.' And he was really mad at me. So he went out and got a piece of glass and cut his wrists and came back in. 'See, I'm cut now; now you got to take care of me.'*

Here the only way patients can show up as in need of care is to display evidence of a biomedically comprehensible and fixable problem. Harry realizes this and complies, passing the "entrance exam" to prolong his stay in the safety and security of the ED. But the respite can only be temporary. The nurse is not unsympathetic to Harry's plight, and realizes that the reason for it is the state-imposed "homelessness" Harry feels at the loss of his longtime institutional home. But the ED is not a home, and thus ED care providers are left holding the tatters of what was thought to be a safety net.

Patients like Buddy and Harry are not people whom traditional psychotherapy is going to "fix," they are not people that traditional biomedical therapy is going to "fix," and it is possible that they are not "fixable" in normative terms at all, but their visits to the ED are meaningful insofar as they represent appeals for someone to recognize and respond to them in their distress. This is an indirect form of self-assertion. The ED is seen, above all, as a place to "get help." ED personnel are viewed by themselves and others as society's "rescuers," as was discussed in Chapter Seven.

In many ways, medicine is a remnant of the sacred, possessing broader social authority than religion and recognized as a social good. But like the Wizard of Oz, providers cannot truly offer deliverance, and it is becoming more and more difficult to offer even caring technological "fixes" to those who merit them. What has changed is that there are now more people in need of rescue and fewer resources with which to rescue them, leading to a situation in which the rescuers are narrowing the range within which they recognize the rescueable-- at least partially because they are in need of rescue themselves. When the template for recognition is so narrow, patients with more complex needs may feel they have no choice but to resort to harming themselves in order to be recognized as in need of help. Recall Jack's (Chapter Four) dread of becoming a "product of the system": here is another version of that story.

Sustaining the Narrative

Providers flooded me with stories about remembering these patients, about wondering about them when they were not seen for a period of time, about following their course when they were hospitalized. It became clear to me that, despite all the anger and frustration providers feel toward "frequent flyers," these patients *matter* to them, or they would be unable to produce such rich narrative accounts of their experiences with them.

One day during my fieldwork, I was sitting at the desk as several nurses talked about the death of a "frequent flyer," a young man with alcohol problems and a seizure disorder who had died recently of sepsis after a short hospitalization. "They laughed in the unit [intensive care unit] when we called up to tell them to tell him we were thinking of him," one nurse said. "They thought we were kidding. They didn't realize we *know* this guy really well. They didn't know what to think" [Fieldnotes]. I heard about one nurse attending the funeral of a "frequent flyer." Another nurse said, on hearing about this:

> *Nurse: Sometimes with the, with the critical patients that I've had direct family contact with, I always look in the obituaries, look for them and see where their funerals are. I've never gone. But it's kind of like you always think, during that period of time, on that day, you know, you kind of think of the person, or think of their family. I've never gone to anybody's funeral. You kind of feel like you're there spiritually anyway.*

Still another nurse, telling me what she knew about Catherine, a chronic alcoholic patient with multiple other chronic debilitating conditions, remarked:

> *Nurse: Yeah, I was thinking I should probably even go to Catherine's [funeral]--and see if anybody's there. You know, you feel like--*
> *I'll tell you something. One time Catherine was--she--everybody told me how beautiful she was, used to be. So one time I said, 'Hey, Catherine, I want to see pictures of you. Next time bring in some pictures.' And she was drunk; you know, I thought she'd never remember. Next time she comes with--you know, well, these guys [paramedics] are pushing her in. She brings out these pictures.*

In asking Catherine to bring in a picture, this nurse reveals that Catherine is already a member of a community of care. She reminds Catherine of a past which anchors her in time and human relationships, including relationships with other nurses who cared for Catherine in the past and whose memories are part of the collective history of the community of care in this ED. She allows Catherine the opportunity to show up as someone who has not always been the way she is now, deteriorating and drunk; she recognizes Catherine as someone special, someone with a story worth hearing.

This request also is informed by a kind of practical knowledge that draws from experience. In making the well-founded assumption that Catherine *will* be returning to the ED again, in assuming that there will in fact be a "next time," the nurse draws on both her skilled understanding of the usual trajectory of chronic illness, learned through experiences with other patients with similar disease processes, and her understanding of where Catherine as an individual is located along that trajectory. She knows, for instance, that

Catherine is neither cured nor terminal. She has some idea of how Catherine copes with her illness, what she looks like when her blood alcohol or her kidney function tests are at a certain level.

But she also draws on a kind of personal background understanding about Catherine and her relationship with her. Even though she admits she does not fully understand why Catherine comes to the ED over and over, the request for pictures is an invitation to participate in a culturally meaningful ritual, the sharing of personal history through photographs, that we normally associate with the institution of family. Part of the background understanding this nurse brings to her seemingly casual request, as I learned through participant observation, is that Catherine's family relationships are estranged and conflicted. Extending this invitation denotes acceptance of Catherine as a member of the ED "family." This kind of story draws attention to the way nursing as a practice often bridges the gap between public and private. This aspect of the relationship between ED nurses and "frequent flyers" will be further elaborated later in this chapter.

In turn, by bringing in the pictures on her next visit, Catherine recognizes the nurse as someone she trusts and with whom she shares part of her history. Being a patient puts one in a vulnerable position as one asks for help from others. Here Catherine allows herself to be even more vulnerable, as she opens part of her personal history to the nurse. By sharing her pictures, Catherine also allows the nurse to show up as someone memorable, trustworthy, and caring. She responds to the invitation to participate in the ED community of care.

Temporality

Tanner, Benner, Chesla, and Gordon's (1993) work on knowing the patient uncovered the way skilled clinical nursing practice is based on particular, situated, knowledge about the individual patient as well as on more formalized, decontextualized data. Their work was conducted in intensive care units, where nurses, patients, and families may be together over days, weeks, or months. The ED setting, with its constant turnover of patients who are seen in relatively brief episodic encounters of minutes or hours, might be thought not to lend itself to the acquisition of this kind of experiential, situated knowledge. Yet such understanding is critical to the skilled practice of nursing in any setting.

This may be one of the reasons why ED nurses have such rich stories about "frequent flyers." Engagement with most ED patients is much more limited, both by structural constraints (caring for multiple patients at the same time, with limited staff) and by temporal constraints (constantly preparing for the arrival of new patients). But when nurses are unable to engage with patients, they may feel unable to work out in practice what it means to be a nurse, as opposed to what it means to be a technician, for example. Estranged from the moral sources embedded in the tradition of nursing practice, they may "burn out" and become even more disengaged, simply doing "tasks." "Frequent flyer" patients offer ED nurses the possibility of a kind of engagement that transcends some of the constraints of the setting, even as they challenge their moral and social sensibilities. Sometimes, though not often, the most repulsive and repellent become the most endeared by virtue of shared history.

"Time," observes Ricoeur (1984), "becomes human to the extent that it is articulated through a narrative mode" (p. 52). For many of the patients in my study, the temporal structure of day-to-day life was disjointed; they appeared suspended in a kind of perpetual time, in which events swirled about them as they struggled to stay alive. Likewise, the ED setting is temporally discontinuous; though each day may be marked by certain regular events, such as the changing of shifts of work, the rapid turnover of patients and the constant anticipation of change mean that providers may have difficulty even remembering patients they cared for a few hours ago.

"Frequent flyer" patients thus serve, for ED care providers, as a kind of temporal touchstone; they return often enough to be remembered, and their lives sometimes become the trajectories along which other events are emplotted. For example, in the group interviews with nurses, they several times referred to a past period of time as, for example, "the Jerry [a "frequent flyer"] days," or recalled when a coworker began working there by figuring out whether or not they remembered a particular "frequent flyer."

For patients, the familiar relationship they developed with the ED permitted them a place in which some version of a coherent narrative of self could be sustained. Lacking families, occupations, and often lacking homes, they sometimes found in the ED setting a place where their story could be told, where it would be remembered by someone.

Familiarity versus Recognition

Almost all of the patient participants in this study made some reference to being "known" in the ED or otherwise having a familiarity with the place or the people who worked there. "They know me here," I heard over and over. None of the patients' stories reflected this as a negative; that is, they did not consider being "known" in the ED to be indicative of any problem or "bad" behavior on their part; for many of them, this seemed almost a source of pride. Sometimes this familiarity is considered a real advantage. One 18-year-old female suggested that being known could expedite and even personalize her care:

> *Int: Do you think it's different coming into the emergency room, having been here before, than it is for somebody coming here for the very first time?*
> *Sylvia: Yeah, because they know all about me and they can tell me what's wrong sometimes without examining me, and they'll say, 'Well, Sylvia, it's such-and-such. Why don't you go on home now.'*

Setting aside the question of whether under these circumstances Sylvia is being properly evaluated in a medical sense, this points out the way patients who are familiar may be treated differently than patients who are "new." However, this familiarity is not always the same as positive recognition, as Caroline, a 46-year-old woman with incapacitating lung disease, alcoholism, and metabolic problems, helped me to see. On the day I interviewed her, Caroline came to the ED intoxicated and complaining of several physical problems, including abdominal pain, after she got in a fight with her boyfriend. I asked her what she thought they would do for her in the ED.

> *Caroline: I don't...God knows, I don't know.*
> *Int: Well, what would you like them to do?*
> *Caroline: Give me some help, but tell me what to do 'cause I'm tellin' you something. If I don't get some help, I--Look, I don't know what to do with myself no more. I am telling you, I'm tired, I'm tired, I'm tired, I'm tired. I don't know what the hell I'm'a gonna do next. And I'm tired of drinkin', but oh--I'm tired of drinkin' and I'm just tired, of not realizin'...These people tired of looking here, at me, but you know--?...They ain't gonna do nothin' but turn me loose. He don't do nothin' but turn me loose, but I'm'a tell you somethin'. I'm hurting so bad. But they ain't gonna give me nothin', they gonna do me like they always do.*
> *Int: What do they always do?*
> *Caroline: [adopts mimicking tone] 'Well, Caroline, you've been drinkin' ' --ah, hell, I'm tired of that...'N' see, these people here, lemme tell you somethin'. They don't treat you right sometimes...I'm jes' tell the truth about that.*
> *Int: Well, tell me, what do they do?*
> *Caroline: Oh, they know I'm a, I have a drinking problem. They talk to you like a dog up in there.*

Yet even as she bitterly castigates the ED staff over her previous treatment, Caroline emphasizes her loyalty to the hospital.

> *Caroline: This, it's a good hospital. God knows it is. But I've been there, I guess they're jes' tired of lookin' at me. I'm--well, I can't help it.*

Later she re-emphasizes this point:

> *Caroline: Well, ain't nothin' wrong with this hospital. Ain't nothin' wrong, this is a good hospital. But, Lord, I wish they can find out what the hell they can do with me.*

This intense defense of the institution was common among patient participants. The hospital, in almost every interview, is seen as unqualifiedly "good" even when the person has been somehow mistreated. This was true at both the private nonprofit hospital and the public hospital. There is a way in which these patients recognize and respect the moral mission of the institution even as they tell stories of moral failures on the part of individual practitioners. Caroline does not come to the ED seeking the "quick fix" the ED is set up to recognize the need for and provide; if she yearns for rescue, it is for rescue as a kind of deliverance from the overwhelming problems of her life. Caroline herself cannot figure out "what to do with" herself, but she fervently hopes the rescuers can. Yet she is often resistant to interventions, as she was when the social workers tried to dislodge her from her home and place her in a long term care facility.

Asked to tell me a little bit about herself, Caroline starts out by saying she didn't finish high school and was raised by her grandparents. "My mother didn't give a damn about me," she says, starting to cry. Caroline married a 21-year-old man and had her first child at age 15; she had another baby by the time she was sixteen. Divorced seven years later, her husband "ran off" with the two children, eventually sending them back. Unable to support them, she left her children with her grandparents, moved to another city with a friend and worked in a club, where she says she "kind of got off on the wrong foot...I started drinkin', and partyin', and stuff, and I ended up gettin' shot and cut."

> *Int: So you've been drinking a long time?*
> *Caroline: Uh, ever since I was about fif--fifteen years old. Caught up with me now.*

For the last nineteen years, Caroline has been with the same man, with whom she now lives in a large old house not far from the hospital. Caroline suffers from lung disease and says it prevents her from doing much for herself. I ask her about a typical day:

> *Caroline: I don't do anything, just eat and sleep, 'cause uh, I get too shortwinded, I have emphysema so bad.*
> *Int: What do you do for fun?*
> *Caroline: Watch TV. There's nothin' else that I could do, 'cause see, I can't go up and down a lot of steps...Sometime I might have one, I have one friend who comes to visit, uh, from church. She don't stay very long...'cause see, she's got kids, she has to go home and cook, and she works every day.*

Like Buddy, Caroline, comes to the ED to seek "help," help in its broadest, most global sense, and she does so frequently; more than 20 times in the last one year. The help she seeks, however, is help the institution is not set up to provide. Again, as with Harry, Caroline must present with a medically "legitimate" problem in order to be recognized, but Caroline has so many ultimately "un-fixable" problems that she has a reputation among providers as difficult, a problem patient. Now, even when she presents with a "legitimate" problem, Caroline may not get the recognition she seeks.

Caroline seeks help partly, as I later learn, to escape a sometimes abusive domestic situation, and partly because she has serious medical problems that frequently necessitate inpatient admission. These admissions are a welcome respite from a life of numbing isolation and dependency, broken only by physical abuse. However, because she is so well known in the ED, she fears that she will not be taken seriously, that her problems will be minimized or simply blamed on her drinking and thence on herself, and that the "help" she seeks will be denied. In short, she trusts the institution, but she fears that health care providers' familiarity with her problems will preclude recognition of her needs.

This fear is not unfounded. Emergency care providers have many stories about the risk of jumping to conclusions, making assumptions about patients that later prove to be in error. "ASSUME," goes the old aphorism of clinical education for emergency caregivers, "makes an *ass* out of yo*u* and *me.*" Rather than making assumptions based on what seems "obvious" or even "likely," providers are exhorted to always consider the worst possibilities and rule those out first.

ED care providers have a constant concern with who is "sick" and who is "not sick" and how one tells the difference (Scheper-Hughes & Lock, 1987). Learning how to do this rapidly and correctly is central to skilled emergency practice. "Sick" patients have "real" medical conditions requiring immediate technological interventions in order to save the patient's life or to avert major disability. "Not sick" patients have conditions that, while perhaps difficult to diagnose because their symptoms are confusing or ambiguous, do not require immediate attention in order for the patient to survive. Heavy ED users present providers with a dilemma, because their very familiarity can tempt providers to make the dangerous assumption that they are "not sick," as the following comments by a physician suggest:

> *Physician: There's [a] patient. I can't remember his name right now. But he was a long-standing alcoholic and smoker. Nice guy. Tall, thin, and uh, always came in with complications from alcoholism. Sometimes was admitted, sometimes not. But came in a couple months ago by ambulance, sick. And this is what's tricky about these patients, is that they really are sick patients but we see them for the same things over and over again and we begin to lose a bit of your objectivity in dealing with these people. And this guy was brought in by ambulance. And sometimes they can't express their complaint very well, also. And so it's, it's tough all the way around. And they put him into one of our non-acute rooms. We saw him. He had a breathing complaint; appeared to have pneumonia on examination. And uh, he'd also had a seizure, because he has seizures. Moved him into a*

> *more acute room where we could give him some medicine and stuff, prevent any new seizures in the department, and he promptly coded. Went asystolic just like that. Boom. And uh, got resuscitated successfully, was admitted to the hospital, and died about two weeks later. From complications from ARDS [adult respiratory distress syndrome].*
>
> *But these people, along with their ordinary, run-of-the-mill complications, they're also at risk of catastrophical, life-threatening diseases that can knock them over because they're immunocompromised; they're weak.*
>
> *But on top of that, I think the system--I'm not sure if this should be recorded--(laughs) --the system is not set up very well for that, because, I mean, it's like the boy that cries wolf. You come in enough times and then after awhile, you're not going to get the attention that you would if you had only come in once with a similar complaint.*
>
> *Int: 'Cause people start to say, oh, it's so and so again.*
>
> *Physician: Yeah, it's, it's the same thing. And there's not a lot you can do about it. And you can't point the finger at anybody, uh, either at the nurses or the doctors or even the patient. It's just a combination of factors that makes it tougher for them to get sometimes the uh, attention that they need at the time they needed it. I mean, I can't tell you how many times alcoholics are found down and are brought in and are pushed off into a non-acute room and are drunk, intoxicated, urinating on themselves, and any number of things could be wrong with that patient. But, if you play the odds, you take your time going in to see them, you're going to come out okay. They are going to be drunk, intoxicated and maybe a bump on their head. But every once in awhile...*

This physician's voiced concern is the ability to differentiate a "sick" heavy ED user from one who is not, but there is a subtext about the moral claim of the patient for attentive care versus the practice of relative neglect if the patient is judged "not sick." The moral failure to "see" that something more was impendingly wrong with this patient still worries this physician, who suspects that a collapse of "objectivity" may be the cause. The underlying problem is understood here as an unfortunate side effect of unavoidable structural aspects of the system combined with the personal characteristics of these patients, yet it is still troubling and professionally dangerous. At the heart of the distress this physician struggles to define is a confusion between the *objectification* involved in efficient "body processing" and the *objectivity* cultivated as part of an engaged clinical practice. This struggle points to the limits of knowing inherent in the medical model. Gadow (1985) emphasizes that it is possible to attend to the 'objectness' of a patient's body without reducing the person to an object. The ED culture's overriding emphasis on rapidly identifying medical diagnoses often means the virtual exclusion of personhood in favor of the objectified body; here, the way personhood is excluded from consideration, via stereotyping, becomes an obstacle to diagnosis.

These patients are rendered invisible both by their own acknowledged difficulty in articulating their problems (a function sometimes of intoxication but also, as noted in Chapter Six, sometimes of the strategic necessity for medicalizing collusion) and by their very familiarity as bodies who pass through regularly with the same general presentation. Biomedicine provides caregivers with no language within which to name distress which does not have a clear link to physiologically identifiable processes.

This concern over the "cry wolf" syndrome was echoed repeatedly by providers:

> *Nurse: And the problem is that with frequent flyers, we sometimes miss something because we, you know, get used to them [Mhm.], uh, used to their style, uh, aggressive, obnoxious behavior in some people it may be a sign of stroke or, or, or something. But, for us, it's sort of like, well, that's just the way he is. That's just the way he is. We miss some of the warning signs, you know.*
>
> ***
>
> *Nurse: But the thing about having these drunks that are here every day, you sort of blow it off and put them in the hallway and they're the ones that kind of--if you're busy with other really sick patients, those are the ones that you sort of don't really pay much attention to.*
>
> ***

Nurse: Uh, Ben died.
Int: I heard that.
Nurse: Yeah. That's one of the sadder ones.
Int: Well, tell me about him.
Nurse: Um, he's--you know, Benjamin, he's one of these guys that comes in either after having a seizure or falling down after drinking, three times a week. And, uh, he actually had been here, um, he had been here in the morning for a fall or some alcohol-related incident. He had fallen down or something. So we took care of him and sent him out and, uh, about 2 hours later, he came back in, uh, after--I guess, drank some more and then fell down like five stairs at the bus station. Came in and, um, this time he really had something. He had a big bleed[intracerebral hemorrhage], I guess, and blew a pupil[sign of severe brain injury].
Int: Were you there when he came back?
Nurse: Yeah, yeah. And, um, the scary thing was that he was his normal self, talking and everything, out at triage. And then after he was back in the area, he sort of went down.
Int: Oh, really.
Nurse: Yeah.
Int: So he looked good outside--
Nurse: So he--yeah, he did. He initially looked good, yeah, which is kind of scary. So, you know, it was a good thing that we--I mean, we did a great job with him, you know. He was in a trauma room and, you know, we jumped right on him.
So--that didn't happen in this case but that, you know, just kind of makes you think.

During my fieldwork I had a conversation with an experienced ED nurse about a recent case in which a well-known chronic alcoholic patient had been brought to the ED by ambulance with altered mental status, but because he was "known," they decided to just watch him. Several hours later, when this nurse came on duty, he was still disoriented, his eyes swollen shut, with obvious signs of head trauma. His blood alcohol level was zero. She got a CT [computerized tomography scan of brain] and facial films ordered and it was determined that in fact the patient had a skull fracture, orbital blowout fracture, and subdural and epidural bleeding--in short, a severe traumatic head injury. She felt the situation was mismanaged because the patient is a chronic alcoholic, and physicians and nurses both presumed his mental status was due to intoxication. "These patients are even more vulnerable when they stop drinking," she observed. How could they miss something so obvious? She was not sure. She thinks sometimes people assume they "know" patients like this. "But we really have to be careful to look at the objective picture even if we know the patient...And when we say we "know" a patient: what does that really mean? *How well* do you really know that patient?" she asked.

"Knowing" these patients, in the context of an ED where house staff change frequently and clinical experience in the setting is highly valued, carries a kind of cachet for nurses and doctors. In ED culture, persons with the most experience have higher status and, as Benner (1984) noted in her studies of acute care settings, often take charge in critical situations, regardless of their formal role. Displaying one's familiarity with "frequent flyers" can be a kind of bravado, a way to demonstrate that one is savvy and can't be fooled by appearances or taken in by merely "subjective" (less than legitimate) complaints. Yet, as this story and others like it make clear, breakdown can result when superficial familiarity is substituted for careful--and caring--evaluation.

The suggestion, yet again, that "objectivity" is what broke down in this clinical situation is embedded in the cultural expectation of clinical distance (Foucault, 1975) as an aid to diagnosis. While this distance, as noted in Chapter Seven, is in fact sometimes extremely helpful to evaluation and protective for providers, it alone cannot ensure even adequate care, and its parameters are tricky to establish. Expert caring practices involve a balancing of distance and closeness, a perception of both part and whole (Benner, Tanner, & Chesla, in press). Attributing this breakdown only to lack of "objectivity" hides the ways structural and cultural influences in this setting--for example, the lack of time to spend with patients; the assembly-line model of care provision; the use of "standardized" procedures; the emphasis on biomedical assumptions about personhood and disease--promote objectification, the rendering of the patient as wholly other, an object on which work is done. These influences severely hamper the ability of providers to "see"--or genuinely recognize--a patient. Recognition is neither a radical subjectivism in which providers no longer can see a patient's objective physical status nor a radical objectivism in which the patient is reduced to a label or a mechanistic body; recognition means *meeting*, an ability to see the patient *first* as a fellow human being in need of help (Levinas, 1989; Logstrup, 1971).

Recognition Practices

Being called by one's name is a deceptively powerful form of recognition. Inasmuch as language is not merely designative but constitutive of relationships with others, being called by our name entails the most fundamental kind of recognition. Charles Taylor refers to this aspect of our identity when he writes that

> we learn to talk not only in that the words are given to us by our parents and others, but also in that they talk to us, and hence give us the status of interlocutors. This is what is involved in the centrally important fact that we are given a name. In being given a name we are made into beings that one addresses, and we are inducted into the community whose speaking continually remakes the language (1988a, p. 237).

Being called by one's name may seem the most self-evident and banal aspect of identity; it is certainly the most obvious way, in our culture, to recognize someone. However, when one lives in circumstances of isolation and near-anonymity, something so simple as having someone know and use one's name can be experienced as affirming, as shown by Buddy's appreciation for this gesture.

During both my fieldwork and the interviews with providers and other hospital staff, it was striking to me how well staff remembered the names of "frequent flyers," often even years after the patients had died. In telling stories about their experiences with these patients, providers would begin with the patient's name, or sometimes begin by asking peers to help them recall the patient's name in order to better tell the story; in the absence of a remembered name, the story was less likely to take the form of a narrative of engagement (in which both patient and provider figure meaningfully in an interaction) and more likely to take the form of a narrative of objectification (in which the patient shows up as wholly other, not like the provider). The use of names does not create recognition in and of itself, but it permits the possibility of a connectedness in the situation that anonymity would preclude.

> *Nurse #1: Who's the one on IV--Oh, Darlene Somers. Another one. Do you know her?*
> *Nurse #2: Uh huh.*
> *Nurse #1: Big recently re-visitor lately. Big time. I don't know what she--*
> *Int: Is she a new frequent flyer, do you mean?*
> *Nurse #1: I know she shoots. I know she shoots heroin but I don't know if there's other things that she shoots. And she's here almost, at least once or twice a week with abscesses. And she's just--I mean, she doesn't have a vein left in her body.*
> *Int: Is it somebody new coming in that didn't used to come?*
> *Nurse #1: Um, she's just beginning to become a frequent flyer. Great, wonderful personality. Like, you know, she's always pleasant. She's not really demanding. I also think it depends on how you meet them sometimes. And that fluctuates for me but, you know, I've learned--for some reason I've become a little more aware of-- like last time you used, and are you in pain and, you know, those kind of things. And once you start to--that's how Darlene Somers and I have become connected actually, because she would always come in and I'd be like, 'Darlene, you're killing yourself,' you know? She was here yesterday or the other day, Thursday. And she said 'Hi, [nurse's name], I'm back again.' And I was like, 'What are you doing?!' And she would have just left here 3 days ago.*
> *Int: So she knows your name.*

Nurse #1: Right, and she had an abscess. And she goes, 'well, what do you think?' And I'm like, 'girl, you're killing yourself.'

...

Int: Mhm. Well, how did she react--this woman that you were saying comes in, that you were saying, you're killing yourself. How did she respond to that?

Nurse #1: Well, she knows. But, you know, what she knows is that I'll say, 'Well, you don't have any veins', [for an intravenous line] and she'll go, 'No, a groin line.' And I'll say, 'Well, when's the last time you used?' And it'll be, it started out with, you know, I use humor a lot with my patients which is and is not necessarily the best way to go about it. But I'll say, '--and don't lie!' And she's just up front with me now about whatever I ask her. And I said, 'When is the last time you used?' 'Two days ago.' 'So you're kicking?[withdrawing]' 'Yes.' I said, 'Well, I'll see what I can do about that.' She knows that as soon as I can or as soon that, you know, she'll get her morphine or she'll start to be comfy, feel comfortable.

Int: Kind of like she trusts you now so she's kind of being honest with you because she knows you're going to help her?

Nurse #1: Right.

Int: Like you're not gonna try to punish her or something.

Nurse #1: Right. And it's very hard not to be; I can only speak for myself, but, I mean, I was raised in an upper class white situation. And I've been, I mean, I've always worked in, I mean, I've worked in Harlem, and I've worked here. So I don't exactly know what you want to call it but I've been exposed to--but I still don't have a concept of what it is to live, live in the 'hood, should we say, or, you know, like--I just, I don't have that concept kind of thing. I can be as empathetic, or I can think that I have an understanding about it, but until you're really there, you don't--you know what I mean? So I don't know. So sometimes I think if you're not judgmental about drugs or how they make their money or what they are or who they want to be, you know, I think that has a lot to do with it too. And health--as we as health care professionals, we do--like it or not--you know, we bring our own backgrounds to our jobs. And, you know, we are --I'm sure, as much as we try not to be, I'm sure we come across sometimes as judge and jury. [Mhm.] So just trying to keep that in, in front all the time

> *is kind of hard. But also knowing that you don't have a grip on it is half the problem too.*

Here the nurse recognizes the patient in several ways: calling her by name, as discussed above; using humor; alluding to previous shared experiences; and acknowledging the reality of her pain and need for medical help.

Humor as Recognition

The use of the kind of mock-sternness that the nurse calls "humor," like the meaning of Geertz's wink, is a recognition practice that cannot be prescribed or proceduralized; its effectiveness is contextual and, although it may represent a general approach this nurse uses with other patients as well, its specific content is based on particular knowledge of this patient and its success or failure depends upon the particular patient's response in the situation. Shared understanding is a necessity for humor to succeed as such.

Here it is described as fostering a more trustful relationship between provider and patient. The use of humor in a situation where roles are circumscribed as in the ED can be risky, and the nurse takes the chance that this will be misinterpreted. Yet taking that risk reveals to the patient that the nurse recognizes some commonality and expects that they can meet one another in this space of understanding, still within their respective roles but not isolated by them. The patient, in responding appropriately, acknowledges that they are intimate enough to share laughter and thus enters the space of shared recognition. The potentially adversarial power relationship is defused.

One of my most oddly satisfying moments in the course of carrying out this research occurred during my interview with Sam, profiled in the previous chapter. At one point, after we had been talking for over an hour and he had digressed to reminiscences about his seafaring days, he told a story about a risky shipboard incident and observed, "Well, God must look after me." "I guess so," I responded. Then, after a pause, I asked him, "Do you believe in God?" "Oh, yes," Sam answered, with a twinkle:

> *What was that one I was told before--? Oh--there's a guy on the street. 'Hey! Do you believe in the hereafter?' The person says, 'Yes, I do.' Said, 'Well, I'm here after a quarter; how 'bout it?'*

Sam then burst into laughter, in which I joined, wondering a little at how oddly good it felt just to laugh. There is something even now about remembering that shared moment, at 2 a.m. in the back hall of an ED, when Sam, himself homeless, told me a joke about a panhandler, and we laughed together at the joke and, I think, at the absurdity of life, that makes me ineffably happy, a little sad, and grateful. This let me know that Sam had seen beyond my researcher's mask; I had become a person to Sam, a person he knew well enough to tell a little joke to. It was a small but significant act of recognition, a gift.

Shared History

Likewise, the allusion to the nurse's previous knowledge of this patient places the present interaction within a shared history. Nurse and patient have been through this before and the nurse reminds the patient of this fact by saying, "Darlene, you're killing yourself." Here the nurse is bearing witness to the patient on behalf of herself, yet the balance of wry humor helps keep the exchange from being experienced as censure.

There is also a way in which these patients provide recognition to providers through their shared history. As explicated in the previous chapter, providers in settings such as the ED carry the moral burden of witnessing suffering as part of the larger social function of the setting. The only others who can come close to understanding this particular kind of burden, besides their peers, are the patients themselves, and it is affirming when patients acknowledge this by remembering them.

> *Int: Do they know you?*
> *Nurse: Oh, yeah, by sight. Yeah. And a couple of them know you by name. And even the people that you don't think they know your name, know your name. It surprises you. Either that or-- I keep forgetting my name's not nurse (laughs).*
>
> ****
>
> *Nurse: It's like when you see someone enough times you kind of feel connected to them. So that's kind of how they feel a lot of times when they come here. Oh, I know you, nurse.*

This kind of acknowledgement can be very meaningful to providers, especially in the relative absence of any clear societal understanding of the underlying social functions of their work. Standing out in this way for a patient means that, on some level, one's work has been significant, worthy of doing. In the same way in which patients long to be recognized as unique and worthy, providers long to be recognized as the helpers they strive to be. This is why stories about recognition stand out for providers:

> *Nurse: He had super, super bad asthma. And it was almost like--I don't know if he had a death wish or if he, he liked that bringing it to the edge challenge or what. Um, because he was a very, very nice person. I don't think that he was, and he was at least of average intelligence and he had bad, bad asthma. And it was almost like he played a game of let's see how close I can get before I have to go to the emergency room. Refused to take his medication the majority of the time. Eric Hughes. And he was a very, very handsome, charming guy, and, um, he was an incredibly hard IV start. And yet he would time after time after time come in and his asthma would be so tight, he was just barely moving air at all. And, uh, it was really a challenge to, to make him better. And, uh, you always had to do everything triple time because he never gave you any leeway. He was always just on that ragged edge. And, uh, he was probably--what was Eric? Early 50s? And he was a really nice guy, never wanted to be admitted. He always managed to get cleared up in the emergency room, but he would leave here and, again, not take his medication and we all took care of him several*

> *times. Then, uh, Dr. Simon was one of the docs that took care of him quite frequently because Simon worked a lot of evenings and nights. And, uh, Eric had been in several times and, you know, finally at some point said, 'Well, I never see Dr. Simon anymore. Where's, where's ole Doc Simon? I really, you know, I like him.' And, uh, one of the other docs explained to him that Phil had had a heart attack and didn't work here any longer because of the, you know, long-term effects of the heart attack. And, uh, Eric always had a lot of very, very nice gold jewelry. Beautiful rings, beautiful gold chains, and, uh, the other doctor explained to him that, you know, because of Phil's heart attack, he had moved back east and was, uh, had taken, you know, a residency in psychiatry which was going to be less stressful and, and, uh, Eric took off one of his favorite rings and, and gave it to this guy to mail to Phil as a going away present.*
>
> *Int: Really!*
>
> *Nurse: Uh huh. And Phil wore the ring for a long time.*

This is a deceptively simple story that reveals the complexity involved in recognition practices. Here the physician provider, though a third party to the story line, has clearly made a meaningful connection with a patient and, in addition, with his coworkers. His practice stood out sufficiently that this "frequent flyer" patient remembered him and asked about him long after seeing him. There is an important underlying theme of shared vulnerability in the patient's concernful gift of his ring to the "wounded" physician. There is a desire to remember and to be remembered embedded in the giving of the ring, and also in the telling of the story by a third party to the situation. Again, this is clearly not a story about mere reciprocal exchange; a contractarian ethic of "rights" would find the patient's actions inexplicable. This is, instead, a story about an ethic of care (Carse, 1991; Gilligan, 1982), about inclusion rather than claims. Care is here extended from patient to health care provider in a gesture that arises out of mutual recognition and is itself an act of recognition.

Pain Relief as Recognition

Taking up once again the earlier story about recognition practices with a drug-dependent patient, the nurse acknowledges the patient's pain and need for help by arranging for pain relief. This recognition, by which the patient's legitimacy and worthiness of care is unconditionally affirmed, permits the patient, in turn, to recognize the nurse as helper, rather than as antagonist, furthering a relationship of trust which is the precondition for any change in either self-understanding or destructive habits. Pain control issues in substance users are fraught with moral uncertainty for providers; when the focus of their approach is on trying to get the patient to end such behavior, medicating sufficiently for pain relief can appear paradoxically defeating. Yet such a form of recognition allows the patient to show up as something other than "just a drunk" or "just a junkie;" it begins from where the patient is now rather than where providers want the patient to be.

Recognition as Moral Practice

Engaged narratives like this one point to the way positive recognition practices are not predicated on expected ends, or "outcomes," but are experienced as good in themselves. Part of the reason this nurse is able to recognize his limits in the situation and still deal humanely with this patient is that he has relinquished the notion of "fixing" the patient's problems and refocused instead on caring for the patient even if no clear therapeutic end is immediately attainable. Two other nurses allude to this same issue as they discuss the attachments they form with "frequent flyers":

> *Nurse #1: There are people, I think, who push my buttons and I probably, if I can, will go the other way. But then there are other people that I really like even though they are homeless or whatever. But, for some reason, I'm attached to them like they're my family or something and I--*
> *Nurse #2: I'm not going to (inaudible).*
> *Int: Talk about that. Talk about like they're your family.*

Nurse #1: Well, you see them every day so they--you get to know them. You know what they did before they were an alcoholic. You know kind of the issues in their life and you--

Int: Can you give me an example?

Nurse #2: Who's the guy who was an architect here before and built some incredibly wonderful building in the city? I can't remember who designed it.

Nurse #1: I don't know but you know like, I think Joey is a good example, even though he's sober now, because he came in a lot. And even though he was a drinker, he was always really nice. And he talked about his wife and, you know, just--and he would always ask, oh, and how are you, and he just --you know, he appreciated the care. So you really developed this sort of attachment to him. And I always felt really bad when he fell off the wagon. He'd say, I'm sorry, I'm here again. But, you know, I couldn't do it.

Nurse #2: It's like he had some--he knew he had a problem but he had an insight into his lack of control in a way. And I don't know, I guess that's sort of the key thing for me personally. I don't know about you, [Nurse #1], I think you're a little bit nicer than that. But I just like a little insight and a little effort, you know. And I think it's, for one thing, I guess for me, I need validation that what we do--you know, is worthwhile.

Nurse #1: --Works.

Nurse #2: It's not even <u>works.</u> *I'm not so sure that that's something that really does work for what we do.*

Nurse #1: Right.

Nurse #2: I think that's another issue.

Nurse #1: But it's meaningful.

Nurse #2: Well, yeah.

Nurse #1: And I think with Joey it obviously was very meaningful and he not only appreciated the care but he was willing to help himself, and he would be sober for a month, and then he'd fall off the wagon and come back in.

Nurse #2: It depends on, I guess, if you're kind of goal oriented or if it's just okay to let people be and that your job is your job and that's what you do, and that sort of thing.

Here the nurse explicitly draws the distinction between what "works" in the sense of achieving a particular instrumental ("goal oriented") outcome determined by the system and by providers, and what is "meaningful" in terms of fostering the relationship between provider and patient. The former emphasis leads to situations in which both patients and providers may feel manipulated, duped, mere raw material to be used; the latter permits the possibility of mutual recognition and even appreciation by allowing the person to *be*. Paradoxically, an overemphasis on outcomes, with its subtext of provider and/or institutional control, may actually limit the patient's possibility of achieving such change, because it offers a false kind of promise of deliverance that providers cannot actually deliver and patients cannot yet--and perhaps will not ever-- imagine.

The nurse also alludes here to the important link between narrative understanding and recognition practices. Once we know someone's story, once we begin to situate them in a coherent narrative, they can no longer be viewed as entirely other. As interlocutors, we have entered into the story with them. They are still other, but not wholly other; they become members.

The Nickname as Recognition Practice

The following passage illustrates another form of recognition practice:

> *Nurse: Hmmm. (pause) Well, one of our frequent flyers is Jimmy Green, and he--he's about a 40-year-old guy and he's a drinker, and he always falls down and hits his head. And I think I've known him since I started working here. I think I've known him 9 or 10 years. And he can be incredibly, verbally abusive when he's really intoxicated, when he comes in. For some reason, I have this rapport with him that--and I call him 'Brown Eyes' and I'll look at him and he'll be in C-spines [strapped to a board to stabilize the cervical spine, a routine prehospital procedure until spinal injuries are ruled out] and I'll look at him at triage. And for some reason I can just totally calm him down. I'll go, 'Hey, Brown Eyes!' And he'll look at me and he goes (shouts) 'Hey, how ya doin'?' And he really kind of calms down and*

> *he lets, you know, for a period of time, he'll let whoever is taking care of him take care of him.*
>
> *Int: Calms down, like he's shouting or--?*
>
> *Nurse: He's shouting and screaming and yelling, and, you know, swearing mostly. And in an incredibly loud voice. And then once you, you know, just treat him like your friend, or like, you know, you know him or you're a friend, and he recognizes you, it seems, he seems to calm down for a period of time. Sometimes he'll stay calm and other times he'll just, you know, escalate once he gets back to the treatment area.*
>
> *Int: There's something about you recognizing him.*
>
> *Nurse: Yeah, something about the familiarity--you know what I mean--of, uh, and I think, you know, sometimes I think, that's why, number one, with our repeaters, frequently there's no place else for them to go. And we're almost at times part of uh, their dysfunctional family. You know, they are kind of--we probably know them just as well as most people do, especially the people that come in real frequently.*
>
> *Int: What else do you know about him?*
>
> *Nurse: I knew he was a Vietnam vet. And I heard that he was a decorated Vietnam vet, like a purple heart. I know he's from here originally. And he's got a horrible drinking problem.*

A nickname, as it is used here, is a recognition practice in that it reminds the patient of shared history, invites the patient to respond to this intimate code, and implies a kind of automatic acceptance into the ED. Addressed in this way, the patient calms, even if he has been aggressive; this form of recognition seems to assure him of a kind of safety. The nurse does not know this patient's history in any detail, but her actions reveal an embedded understanding of the fear and helplessness that contribute to his aggressive behavior. There is a terrible isolation in being unknown by others; the fact that this nurse knows even a few small details about this patient's life, and remembers them, means that he is not just "any patient" to her: he stands out as worth remembering something about, and he is therefore able to show up as a member of the ED "family." We will have more to say about this later in this chapter.

The Limits of Control

In the group discussion, two other nurses talked about how they maintain a caring practice in this setting:

> *Nurse #2: It's your attitude.*
> *Int: Yeah?*
> *Nurse #1: I think time. I think time and experience, don't you?*
> *Nurse #2: Like you said, first you rely on how you were brought up and that, and it's kind of shocking. But then you see like, you know, these are real people. They are not gonna go away, and you're gonna see more and more of them and you're trying to understand where they're coming from.*
> *Nurse #3: I think some of the younger nurses are less patient.*
> *Int: Are less patient?*
> *Nurse #1: Well, I--but I think that comes from exper--I remember as a new ER nurse, it was like-- it's frustration. I, you know, I think that you, you know, I look at myself as a finger in the dike. I can only bandaid the problem. I know it's gonna come back. Nothing I do is gonna change that, and I think you have to get to that acceptance thing.*
> *Int: As opposed to (inaudible).*
> *Nurse #1: I'm not gonna change the world and I think when you're new in your job or you're new in an ER practice especially, you know, if you're in inner city, you know, it's overwhelming. And I think you think--what do you mean you can't change your own bed? I remember going through that frustration for a long time myself. And it's just that I've been doing it and realizing I'm not gonna change the behavior; it's not gonna go away. So what's the easiest thing to do is-- kill 'em with kindness and give them what they want and realize they'll be back in a week. You can only do what you can do.*

When nurses are able to recognize the limits of their control of patients, they are able also to acknowledge the limits of their patients' ability to change when told to do so--a recognition of human fallibility and the contingency of choices. The role of omnipotent rescuer, while attractive, leads to despair as the futility of one's grand efforts on others' behalf becomes apparent, as we saw in Chapter Seven. Giving up that role for a more situated, delimited, immediate involvement allows providers the freedom to accept patients on their own terms. When the aim of providing care becomes understanding, rather than control, new possibilities for both provider and patient are revealed.

Another nurse talked more explicitly about the limits of control when discussing the way she tries to care for chronic alcoholic patients:

> *Nurse: I think it's important to, number one, when you approach them, to be on their level or a little bit below their level, so that you don't--*
> *Int: You mean as opposed to looming over them.*
> *Nurse: Right. Yeah, so you don't, you don't, uh, put them in a defensive position because most people who, who are not euphoric with their alcohol tend to be fairly agitated and irritable. And if you start looming over them and proposing that you are a better person or that you are an authority figure, you've already lost the battle. There just isn't any way that you're going to win that. You're going to have problems from the very beginning. I usually walk in an introduce myself and sit down and, and, uh, go through the chitchat. And always at some point in time, you know, you have, you have to talk about what they've been drinking, what they've been taking. And I always put in there, (assumes lighter tone) 'Well, did you have one or two [drinks] for me because I really need it tonight. I'm just not, this has been a horrible, horrible period.' So, you know, it makes them feel like--*
> *Int: Use a little humor.*
> *Nurse: Yeah. You're not putting them down for what they're doing even though you think they shouldn't.*
> *Int: But you may get a more truthful answer too.*
> *Nurse: Well, sure. And you need a truthful answer and you need to know where they are, you know, so that you can express--I don't really care how much you've had to drink. The object is I need to know so that we can get to the bottom of what's going on here. It's important. [Mhm.] Not that you drink, or not that you've had that much to drink. It's just important so that we can apply it to both. And, uh, I usually get along pretty well with them. There are some that I battle out with but--*

Int: Now, see, it's interesting that you say that because I know, from my experience—I, I think I tend to be more on this end of the camp. But there are definitely some people that really feel you have to be very, you have to be very firm and confrontational, and, uh, and, uh—

Nurse: You know, I've never felt that way. I don't think confrontation—

Int: —you know, (inaudible) get away with, uh, these kind of—

Nurse: Yeah. Right, right.

Int: —sort of school of thought.

Nurse: I don't let them sort of cross the lines too much. They stay within my boundaries. But you can do that very easily. [Mhm.] I mean, it's not, it's not as if you cannot control them because you can. And those boundaries— you may have to set limits with them. But if you, you've established a relationship with them to begin with, that's not authoritarian, the boundaries are easy to set. [Mhm.] Um, but you're right, you know, that control is a major issue. And I came from a school many, many years ago that, um, you control things sort of on the periphery, not by authority. You get along better.

Int: Well, you know, I think I, I really tend to agree. But it's interesting to watch because in practice it seems like that plays out very differently.

Nurse: It's exceedingly important with, with this type of population, the ED abusers because it is their form of control. And you're trying to control their control? It won't work. What are you going to gain— beside hassle? And neither one of you need any more hassles. God only knows.

Int: Well, now, let's back up there because that was really interesting what, um, when you say it's their form of control. Uh—

Nurse: Well, a lot of these people who come into the Emergency Department don't have any control in their life, and the only control they have is to, to access something that makes them feel comfortable. [Uh huh.] Something that, uh, gives them something. Let's face it. We give them something. Sometimes we give them narcotics; sometimes we give them warmth; sometimes we give them socialization; sometimes we take them away from a fear, as in domestic violence. We do a lot of comfort measures, and that's their form of control for themselves. You know, it's abstract [Mhm.], but it's true...

> *You have to treat their needs, and part of their needs is, is why they came here. The underlying why they came here, not the reason they say they came here. And I, I'm not a firm believer of some of these people, unless it's very straightforward: 'I chopped the end of my finger off— that you ever know the why they came here. It's not clearly a present type thing. So.*
> *Int: Uh huh. It's something you have to get to—eventually.*
> *Nurse: And maybe you won't. But as long as they're happy then you know that they're probably satisfied in meeting whatever needs that they wanted to begin with.*

This nurse has developed a practical definition of control that is neither dominative nor adversarial. Instead, she understands control as the way the ED provides safe external boundaries for people whose personal boundaries are disturbed by mental illness, substance use, emotional or physical abuse, or social isolation. The actions she describes, such as sitting down, asking if the patient "had one for me," and "going through the chitchat" may appear trivial, superfluous to the "real," "objective" business of quickly determining what is wrong with this patient, but they allow for a level of engagement that avoids the dangers of superficial familiarity discussed above. These are recognition practices in that they invite the patient into a space of shared experience, of shared humanity. Yet such a stance also respects the patient's individuality insofar as it is not overtly normative; that is, the nurse does not expect the patient to desire sobriety, for example, or to have full self-understanding of inner psychological needs; again, the patient is accepted on his/her own terms as the nurse accepts the limits of her control.

Recognition and "Compliance"

The willingness to help even symbolically with needs that are not culturally defined as "medical" or "emergency" needs is another form of recognition. A social services worker described how a nurse taught her something about recognizing patients' functional capacities to comply with recommendations for care:

Social Worker: Well, you know, I--something really struck me yesterday. I don't know if you know [nurse] or if you'd talked with her.

Int: I, I just know who she is.

Social Worker: She's very kind to the patients. And she has some kind of sense of service which I think many of the nurses don't have. And I think there's a, there's a pretty snotty attitude. I think that we're real confident at, um, emergency type work and assessment. But the attitude toward the patients, I think has gotten--I don't know if it's more disrespectful, but it's more tolerable not to think more about what people need. And I realized I was getting into it.

There was a woman yesterday, or day before, who had a Bartholin's cyst. I think she was crashing from crack because she just couldn't wake up in the waiting room, (inaudible). And I told her, 'cause she had to have surgery and she was in so much pain, I'd get her a hotel room for three days, which I almost never do. But she had to go and make her surgery appointment. Um, and if she did, you know, then I would.

So I'm looking and I got her the hotel room anyway, but she didn't know it. And I'm looking and she's still nodding out in the waiting room and I just felt so fucking pissed off, I was just feeling like, you know, 'Fuck you, [patient], you know. You didn't even go get your appointment; you're not getting your hotel.' And then I was talking to the clerk over in Social Services, I said, ' Well, I don't know what to do with this hotel, shall I give it to her anyway?' And, [name] is the clerk and she said, 'Well, just make her go get her appointment.' So I paged her and then I said, '[patient], you have to get your appointment or I can't give you a hotel.' And she's still looking at me and I go, she's not going to make it to go get her appointment. I mean, who am I talking to? It's like giving these instructions to these patients, and we've done our job, we've given the instructions, totally uh, missing the fact that <u>this person can't do this</u>.

So I realize, shit, I have to walk her back and, uh, I have to walk her back and make this appointment with her... It's interesting. I have to take her back to get the appointment made or she's not going to make it. And, as I take her back, I--[nurse] was there with another patient who was sort of similarly out of it. And, uh, an old man, you know. And she was doing something like that for him. Then I remember when I first came here,

> *[nurse] was the charge nurse a lot. And there used to be sort of an attitude of --don't just take some of these old, really out-of-it people and tell them to go make an appointment upstairs in two weeks. I mean, get real! They can't. That's why they're here, uh, so much. So, you know, do more. Uuuh, so that we don't have to do it all again. So I think a lot of times we treat these people like they're more high functioning than they are because we have this moralistic attitude that, God, see she's--like I was yesterday, I mean, it's not from Mars, to me, how you get this attitude. Like, 'oh, well, she's sleeping off crack. Why should I go any further to do anything for her?' There's this sort of split judging the patients, and then judging them 'cause they don't deal with the instructions we give them, and then-- And then I realized how little of that I see now, of the nurses sort of doing the extra step at the end of the discharge of taking the patient to wherever or, um, just feeling like you haven't finished when you've just written out your instructions. But, you know, think for a second, is this person really gonna do this? You know, I know [another nurse] always does that. I don't know about the other nurses, but I've certainly heard some things that are just off the wall.*

This rich narrative begins with the social worker assuming a control stance in which the interaction is characterized by an expectation of reciprocal exchange and bargaining. The patient shows up as "just a crack addict," a totalizing label that sets exclusionary moral boundaries and calls for enforcement of rules. Compassion becomes confused with condoning addiction and dependency. The plan is that the patient will be rewarded for taking responsibility for herself. If the patient complies, the social worker will arrange the hotel. If the patient does not comply, runs the accompanying subtext, she does not deserve care. This is reminiscent of the analysis in Chapter Six where the drug-addicted patient is excluded from care because she does not remove her dressing as instructed. The patient does not comply, however, forcing the explicitly moral aspects of the control stance to the forefront.

The patient is described as just "looking at me" in the absence of engaged action. In the context of the explicitly voiced expectation, by the social worker, of reciprocal action by the patient, the patient's lack of response signals utter nonrecognition. The patient suddenly shows up as not even knowing how the game is played.

Here lack of recognition on the part of the patient actually prods the social worker into recognizing the patient's embodied incapacity for compliance, breaking through the borders of the label. Even overt resistance might have been interpreted as a kind of distorted recognition, manipulative behavior or a "scam," thereby hardening the adversarial stance of the social worker; in the absence even of resistance, there is simply no possibility for meeting under the commodity-exchange rules set up at the beginning. The relationship is simply too unequal, and the social worker is solicited by the moral mandate to re-examine her own understanding of the relationship when the patient's response seems incoherent.

The social worker also calls attention to the way caregivers can be morally prompted not only by patients themselves, but by the moral actions of their peers, understood as part of the traditions of a practice. However, when caregiving is reduced to a series of discrete tasks, those moral sources of practice are lost; clinicians can lose sight of the larger aim for the sake of which these tasks are being done. This is why business-manufacturing models of hospitals may actually contribute to reduced "efficiency" and return visits, as caregivers take up an understanding of themselves as assembly-line workers. As this story shows, effectively preparing a patient for discharge from the ED cannot be reduced to merely handing the patient a piece of paper instructing them to make an appointment. Many of the patients who use ED services heavily, as we have seen, have complex needs and, often, cognitive impairment. The model of informed consumer, as noted in the case of Matthew (Chapter Seven), is not only inadequate to capture these persons' relationships with the medical care system: it is morally reprehensible in its implications.

> *Social Worker: My impression is they do kind of get sick and they keep bouncing back. And, uh, and they're just too untogether to like make appointments. It's just not going to happen. Which is why I think it's great we have this wound clinic now, and a few more things that are flexible like that. Like let's face the fact that we can say, 'Oh, yes, we made an appointment.' They're not going to go. They don't know what day of the week it is. You know, this is nuts. Uh, this isn't how to do it.*

The Moral Pathologizing of Dependency

Providers are not alone in struggling with the issue of how we can make sense of dependency. Our culture has pathologized almost all forms of dependency, with the possible exceptions of infancy and early childhood. Efforts to re-frame the habitual language in which we talk about dependence on others (such as substituting "differently abled" for "handicapped" or "disabled") are attempts to escape the moral burden of being a burden in a society where everyone is expected to be independent and self-resourceful. This is another consequence of the predominance of instrumental thinking. Insofar as dependent people interfere with the goal of ultimate efficiency, they are seen as problems and their contributions are rendered invisible. The most extreme example of this lies in Hitler's "merciful" (and extremely efficient) extermination of the mentally ill and all those he declared "other."

In the following story, a nurse talks about creating an alternative vision of the patient as inherently, innocently dependent that helps her sustain a caring attitude even under adverse conditions:

> *Nurse: Um, when you see these frequent flyers and people that--or people that just really irritate you at triage, abusive people. Sometimes I find*

> *myself just going ahead and getting irritated with them and kind of feeding into their anger, but other times, when you really think about it, I try to think of this person as someone's child. You know, you look at them and they're like saying, 'fuck you' to your face. And you try to think of them as an infant. And it kind of, kind of puts things back into perspective because we are pretty much—no matter if you're a frequent flyer or not, we see the worst of people. And you know these people are not like this all the time. (pause) No one is.*

This story contains a recognition of the inherent dependency and fragility we all share as part of being human. Thinking of difficult patients as "someone's child" allows this nurse access into a different way of understanding that dependency and the anger that often overlays it. In the same way in which a parent is able to recognize that a child's anger is not wholly constitutive of the being of the child, this way of reframing the situation allows the nurse to feel caring and compassionate rather than only feeling abused, angry and helpless.

The patient is thus recognized as needful in a way that the implicitly adversarial, exchange-based stance does not permit. While this could also be interpreted as a way of reducing the patient's status in the situation, it does not seem to serve that purpose in the narrative. Rather, the nurse suggests that taking up this way of relating in imagination opens up possibilities for relating to the patient more positively in the actual situation. The infant is, on a cultural level, almost the only acceptable version of dependency we have; even there, Americans encourage initiative and independence. What we struggle for is a way to talk about dependency throughout the lifespan without feeling overwhelmed and abused for doing too much or guilty for doing too little.

> *Nurse #1: Well, it was strange. It was almost like—what she would do—I just remember this one time getting mad at her but not being able to really tell her how I felt—because she was in the room and I was just like getting there. And it was the kind of thing where she started calling. You know how*

> *certain patients just call out your name, and I went over, and she's a little drunk. And she had urinated all over herself. And I mean, I was right there. And then she goes into this (high whining--mimics patient) and then so she gets this sort of pathetic kind of cry and just crying and crying. I'm like--you know, I change her, and then, you know, she would do that again. She would have just that--that would just like push your buttons.*
> *Nurse #2: Yeah, you know, and it got a reaction from you and that's, I think that's a form of comfort for some of these people. Because you know them so well and you know that they're trying, trying to get something out of you. So you're not--so they do something to anger you so they get something out of you, anyway...And then when she got admitted to the hospital, when she knew she was getting admitted to the hospital, her attitude changed. And she was apologetic. Very apologetic. 'Thank you very much.'*
> *Int: So being admitted was important to her.*
> *Nurse #1: I think it took her away from the situation.*

Here the nurse encounters infantile dependency in an adult, and although she recognizes some of the underlying reasons for such behavior, she is repelled and disturbed by it. Such behavior was common in provider stories about "frequent flyers," begging the question of whether the failure to recognize such patients as other than burden pushes patients toward increased dependency in a desperate bid to be recognized as needing and worthy of care. The issue here is not whether it is "normal" or "acceptable" for an adult to wet the bed, but whether we can find new ways to interpret dependent behaviors that permit the possibility of recognition.

Looking versus Witnessing

Sometimes providers simply seem to have no opening within which this can happen, no break in the otherness through which likeness can take hold:

> *Nurse #1: Case management... I don't know whether or not it has, you know, much of a degree of success. Some of it has been, but apparently case management has absolutely, completed, reneged, on Alice. They have absolutely discerned that she has zero motivation. And I think they'll take*

anybody like with one percent and up, and that she has absolutely zero motivation for detoxing or anything. She just knows she's going to drink herself to death. And I don't think it's conscious because she doesn't have a lot of brain cells left to, uh--

Nurse #2: She's started to deteriorate..

Nurse #1: She has, yeah, she has. kind of like little balloons. She's got that shelf kind of alcoholic belly, like the beer belly type of thing.

Nurse #2: Plus she smokes like a fiend.

Nurse #1: Yeah. And she, she comes tottering up to the triage desk, and you know you have to sign her in sometimes, and sometimes she's like semi-sober with just a whiff of alcohol on her breath, and you know you can kind of like get her escorted out if she won't leave. Sometimes she'll sign in and she'll be put [on a guerney], pee all over it, and then get up and go have a cigarette and never come back. You know, and most of the time you have to watch to make sure she's able to like navigate well enough. Either that you have to run out and grab her and put her in the bed and tie her down and then wait for the whole detox--.

Nurse #2: The last four times when I've seen her, she's been hypothermic.

Nurse #1: Yeah, then, then that's heralding the end; it always does, is that hypothermia in the winter time. It's--

Int: You've seen that before?

Nurse #1: Yeah. There's something about it. It's like with the chronic alcoholics, the ones who are--. It's like Jerry, he finally died in the winter. Mid-January. And it was a very, very cold spell, really cold spell. I can't remember what year it was. Anyway, it was really cold. That usual snap that we have, that just bone chilling cold. And that's probably what's going to happen to Alice after this really nice warm weather spell. That's just generally the trend. It's like when they start getting the dwindles and start looking kind of bad. And you think, uh, uh, no way they're going to make it through a cold spell in the winter. That's really it. It'll probably be true. Oh, we didn't do a ghoul pool on her or anything like that, but there are sort of bets, you know, on the side--

Int: A what?

> *Nurse #1: A ghoul pool, you know where you pick somebody and say, this person is going to die and whoever gets the closest to the date, you know, wins a pool. Although I think it's illegal so we didn't do that.*
> *Int: Illegal? (group laughter)*
> *Nurse #3: Or immoral.*

I ask if they know anything about Alice's background or story.

> *Nurse #1: No! That's the interesting part. Is the-- the things, I think, that we know about her--in fact, I don't know her background at all.*
> *Nurse #2: No.*
> *Nurse #1: I have no idea about her family. Whereas, you know, some of the people who come in here, you really do know a little bit about them, that they were married before, or divorced, or, you know, about what they did for a living before they left their jobs and became really bad alcoholics.*
> *Nurse #2: That's because they become conversant when they sober up. Whereas Alice--*
> *Nurse #1: We've never seen her sober long enough or at least (inaudible) look and see whether--do we need to care for her or is she going to like fall over and flop on the gurney. You're always just worrying about either her physical care or to get her out before she has to come back in 'cause she's just such a handful. I don't know anything about her. Nothing. I do know one thing that's pretty sad. Apparently she, uh, you know, is really victimized quite a bit because (inaudible) street, and apparently, you know, repeatedly raped and things like that. And that's a horrible life. So that would be reason enough to make you, you know, check out from reality even more with or without an alcoholic gene, you know. So, I don't know. I think it's a rough life for a lot of people. I think it's a really rough life. Phenomenally difficult; it's just like, we can't even imagine it.*

Alice, for these nurses, is socially, chemically, and emotionally wounded beyond recognition, like a body found in a burned-out building. She has indeed become for them a "ghoul," the living dead, a body animated, apparently, only by the desire for alcohol. Yet she continues to "totter up" to them, seeking something that they cannot give and do not understand. They seem to have no entry point through which to recognize Alice as anything but wholly--"absolutely"--other; she has no known family, no known previous occupation, no personhood for them. Alice has no coherent narrative, no story for them. Their only commonality with her is their mutual embodiment, but Alice's body is experienced by the nurses only as an object of repulsion, not even a reliable, "manageable" machine. Even the element of moral blamefulness is muted here; Alice shows up as utterly without agency in the absence of "brain cells."

This kind of disintegration of personhood is terrifying to witness; it is not surprising that these nurses view their primary task as "getting her out before she has to come back in." They literally cannot "imagine" the lives of these patients. They cannot bear to witness, in the sense of engagement that was discussed in the previous chapter; they can only look and try not to see.

The Disguises of Nonrecognition and Misrecognition

The Danish moral philosopher Knud E. Logstrup (1971) suggests that to trust

> is to deliver oneself over into the hands of another. This is why we react vehemently when our trust is "violated," as we say, even though it may have been only in some inconsequential matter. Violated trust is trust that is turned against the person who does the trusting. The embarrassment and danger to which we are subjected by the violation is bad enough. But even worse is the fact that our trust was scorned by the other person. For the other person to have been able to violate it, our trust must simply have left him cold...And it is a question whether it is not the indifference thus manifested toward us in this violation of our trust, even more than the unpleasant consequences of the trust itself, which evokes our bitter reaction (p. 9).

There is, as noted in the last chapter, a socially conditioned expectation of trust in persons with a particular job, such as health care providers. Persons present themselves as patients trusting that this trust will not be used against them. They present, in other words, with an expectation of the possibility of meeting, an expectation of some form of recognition. This leaves them vulnerable to being taken in by false forms of recognition, as in the following story told by a nurse:

> *Nurse: A frequent flyer comes up to the triage desk. Wants to know blah, blah, blah. Look, look, look, I say, you know, none of these problems really [mean] you need to see a doctor. You need to keep your clinic appointments. You need to sort of take care of yourself. What is it I can do for you? What do you want? 'I, I want something to eat.' Well, you know, this really isn't a cafeteria and, you know, I see that you have more than enough money to buy alcohol. Uh, you know, maybe you should, you know, have a better decision making process and think about maybe buying something to eat and cutting down on your alcohol. 'Fuck you.' I said, well, look. I understand that you're hungry. But, you know, here's a list of places that will provide food. St. Joseph's, St. Mary's, blah, blah, blah. So I give the guy the, uh, the xeroxed flyer of the, of the food places. He looks at me, glares at me, makes a fist, and says, 'But I'm hungry!' Wads up the xerox copy, stuffs it in his mouth and eats it. (pause) As a way of sort of demonstrating to me that, uh, uh, I might have been insincere in tending to his needs.*
>
> *Int: What did you do?*
>
> *Nurse: I called the institutional police to have him escorted out because I thought he was going to become violent. This struck me as sort of psychotic behavior. And he didn't get anything to eat.*

Here the patient initially presents by giving a medicalized complaint, as he has no doubt learned through experience he must do in order to be cared for in some way. The nurse, however, refuses to engage with the patient in the customary way, but cajoles him into being truthful instead of colluding in his medicalization. However, when the patient, believing he has indeed been recognized as a fellow human in need, trustingly confesses that what he really needs is food, the nurse uses this as an opportunity to berate the patient for not "taking care of himself."

This is first of all a story about nonrecognition, but unlike the previous story, in which the nurses are terrified and bewildered by their inability to connect, this story arises out of the subverted nonrecognition which the system of medicalizing collusion encourages. There is no meeting, no recognition of common humanity in this interaction; the agenda is a struggle for control in which the nurse, fearing "manipulation" or a "scam," responds in a countermanipulative way and can only "win" by denying the patient care. The patient's action is a symbolically powerful response to the betrayal of trust, a self-assertion in the face of a failed effort to be recognized. The nurse continues:

> *Nurse: But, as I pointed out, if you start walking down to 11th Street now, you will get down to Joseph's and they will start serving lunch in, in, in 40 minutes. That's about right. We are not a cafeteria. And there are plenty of places that people can go if they want to be fed.*

There is, I would suggest, a qualitative distinction between "being fed" and "eating." For this nurse, the patient's request for food can only be interpreted as repellent dependency. Setting aside for the moment the issues of what is required for persons to utilize soup kitchens (the ability to walk and stand in line for long periods, the ability to control one's bladder and bowels, the ability to tolerate the further social degradation of being publicly impoverished), this story suggests an underlying fear that such social dependency may colonize other areas of life, become uncontrollable, unmanageable, and that if it cannot be kept discreetly "private," it should at least be confined to the social institutions created to keep it from view.

Benjamin's (1988) feminist critique of Western rationality and individualism proposes that the insistence on clear divisions between the "private" and "public" spheres of life reflects a cultural fear of dependency rooted in sexual politics.

> Perhaps... the social provision of nurturance is too threatening a reminder of our early dependency in the very outside [male-associated] sphere which was supposed to be our escape from [the dependency of the private female-associated sphere]. The kind of social support that might spark our identification with the helplessness of the needy is bitterly resisted. This attitude creates a vicious cycle in which the unconscious revulsion against early states of dependency or helplessness is reinforced by the spectacle of those who are left in the lurch. The visible consequences of our failure to provide socially organized nurturance--a safe holding environment--

> intensify our distance and disidentification from those who require support (p. 202).

Dependency as Impedance to Recognition

This culturally determined fear of dependency creates a situation in which caregivers, who are continually confronted with those who cannot care for themselves, wrestle with words to find a way to make sense out of what they do.

> *Nurse #1: But, uh, certainly I think a lot of nurses are fairly goal oriented, there's no question about that. And then some people, just like others, are in it just as a job. And sometimes I think they escape, uh, a little bit more intact because, in a funny way--I know that sounds funny but--because your emotions are what you've got invested in your job and the caring that you end up, you know, kind of like co-addictive in a way. You care about the people a little bit more than they care about themselves. You know, I mean, that's really ultimately what it's really like here. And that's a very difficult situation especially if you spent part of your life trying to get away from taking responsibility where it's not due, and where it's not owed. And I think that's a difficult one because, by nature, what we do is caring. And you hope that that sort of sort of, you know, overflows by osmosis. And that that's something someone will actually learn. Generally, I mean, that's how people learn in life is that if you're attended to, if some of your needs are met, and you go just a little bit beyond just what you need, that you're nourished and that you can grow from there. And I guess, in a way, I'd love to see that as a--I mean, that's so idealistic, you know. And I guess I-- I still think that way underneath. You know, like when I take care of somebody and hope that that happens. When, in reality, the function, the actual function is that you're really just being co-addictive. I don't know if that really makes sense?*
>
> *Int: How do you mean being co-addictive?*
>
> *Nurse #1: By caring about people more than they care about themselves. You hope functionally that that will, you know, transfer by osmosis. But it doesn't. In reality, it doesn't. You don't have enough time to really expose those incredibly needy human beings to the tender loving care that--you know, the kind of mommy things that you need to do to really nurture people.*

> *Nurse #2: But you can't do that in an ER setting--*
>
> *Nurse #1: You can't. You can't do it in the ER, and you can't do it. I mean, ideally I think that's what nursing is sort of like is an extension of mothering in a way. And I think there's that real strong need to really nurture people so that they have that ability to kind of like pull up the boot straps and say, gee, thanks.*
>
> *But you know, there are times I've seen those, in a couple of people who came back--there was this one woman who was really ready to change her life. And you could just tell. I stopped her for a minute. I could tell she was just kind of like getting ready to tear. And really wanted a drug treatment program. And I took about 15, 20 minutes out--I had the time--and I really talked to her, and talked to her about how wonderful it was that she had the motivation and it really seemed like she was ready and things like that. But I can count like three people that I know I've intervened in at a point when they were ready. You know, and they somehow had enough nurturing that they were motivated to make the change, or at least the effort to make a scary change in their lives.*

This is a story about the struggle against the prevailing tide of instrumental rationality, played out in the trend toward viewing medical care as product in an increasingly competitive marketplace. As medical care, especially in institutional settings, becomes delimited by the language of efficiency and business, health care providers are literally deprived of the common language in which to talk about the most morally meaningful aspects of their work. This is evident in this nurse's half-apologetic efforts to find the right way to understand her "idealism," which in the current climate has either been pathologized as "co-addictive" or rendered irrelevant in the press for efficiency. She would like to be efficiently "idealistic," but she recognizes that the kind of "nourishment" her patients desperately need cannot be provided by the "quick fix."

The language of care thus becomes subterranean, something she still feels "underneath." It is significant that the nurse describes taking time "out" to provide support for the woman who was ready to try to change her unhealthful patterns of living;

such support is implicitly seen as external to the "real" work she is supposed to be there to do. Caring practices are reduced to surreptitiously-snatched moments of near-covert connection, morally satisfying but carried out at the risk of sanction and in the absence of institutional and societal support.

> *Nurse: Well, Marty used to be a more frequent flyer, but now he has found himself accommodation on [street]. So he used to be here every day. And one day he actually called 911 because it was his birthday and he was lonely.*
> *Int: Really!*
> *Nurse: Mhm [affirmatory]. And he came in quite the, um, happy person. But he was just lonely! I think a lot of these people, they have nobody. And we are their resource, but they haven't learned, at an earlier stage of life, how to take care of their personal needs. And for whatever reason they have fallen off the wagon and become alcoholics (inaudible)... I was on triage. I triaged him. I said, what are you doing here today? 'It's my birthday.' I said, happy birthday, so why are you here? 'Because I'm lonely.'*
> *Int: Huh. And what did you say?*
> *Nurse: I kind of felt sorry for him. You kind of have a soft spot for some of them. Marty, he can be abusive but he's usually a nice person.*

This is the kind of situation that inspires television news exposes about "abuse" of the "system," fueling taxpayer resentment against the poor. What is lost in these kinds of accounts, and in the ill-conceived policy changes that sometimes result, is the social breakdown that contributes to such poverty and isolation. Institutions like the ED stand as the last places where recognition of vulnerability and neediness can be safely sought, in the absence of family resources and authentic institutions of community care (See Chapter Nine).

Recognition as Standing in for Failing Families

Emergency care providers are often called upon to stand in for absent or failing families. Over and over, providers told me about the way they served as "family" for "frequent flyers," sometimes in surprising ways:

> *Nurse: One [story] is about a frequent flyer who died several, let me see, about four years ago now. His name was George. Uh, alcoholic gentleman who was absolutely charming when he was on the sober end. Uh, blue Irish eyes and we, uh, always teased one of the nurses whose last name was M____ that, uh, if she would just give him a good Irish stew that, you know, he'd never come–that, uh, um, you know, he'd come back to the hearth and home and not have to use the emergency department. Uh, they, of course, weren't husband and wife, but that's what we teased her about.*
>
> *And George was, um, at, uh, last year, I think it was about six years ago now. He would come into the emergency department, found on the street down in, uh, alcoholic [skid row] area, and, uh, of [city]. And, uh, would come in probably, oh, three or four times a week. And finally got to the point of telling him– he was hypothermic, uh, and, uh, just obtunded, uh, nearly requiring intubation. And actually two ICU admissions, the last week and a half before his death.*
>
> *And he actually didn't end up dying in the emergency department but outside. And we had the coroners who came up and asked who this person was. And we were actually able to ID [identify] him. But through his picture, which I thought was pretty interesting. It's like we were his family who actually were able to identify him.*
>
> *And I was extremely saddened because, like I say, there's not very many people that I think are really extraordinarily charming. But when he finally got sober–even when he was drunk he was not a nasty drunk. And, uh, kinda flopped around, sobered up, and then would say, thank you very much. When he left. You never got the sense that he really heard that we were extremely concerned about his drinking. I think he was probably too much in an alcoholic cloud then. But I liked him a lot, and I'm kind of sad that he's gone.*

> *I'm not really sure why he was here. I think his alcoholism probably got the best of him. I'm not really sure that he came here so much socially, although it's hard to not say that because we essentially were his family because we IDed him. Uh--*
> *Other voice: (inaudible)*
> *Nurse: Yeah, I think so too, actually. A lot of people come here for social reasons even if they're sort of like the bad seed of the family. You know, they're kind of like not the well-liked member or something like that. That seems to happen a lot...*
> *You know, even if the nurses don't like them very much, it still seems a place that it's familiar and I think that's probably the key thing about why we see so many repeaters here. You know, the holidays, nobody has families here. Nobody has, you know--all these people, everybody else has family to go home to or to, you know, even spend a raucous day or getting into the usual family fights or, you know, whatever happens amongst families on holidays. You know, both the good and bad. But, um, I think that's truly why a lot of people come here.*

Families are both boon and burden, but here emergency care providers are asked to bear a disproportionate share of the burden of the failing family. Once we understand this, it is no longer surprising that emergency care providers seek in numerous ways to distance such patients from themselves. What is remarkable is that so many still willingly shoulder that burden, searching out ways to preserve closeness and connection. Some days this is taken up as a joy, a privilege in which meeting the other reveals the self as caring and good. Other days, providers "wall off," protecting themselves from the pain of witnessing suffering and feeling helpless. Caring cannot be "decided" in advance; one cannot go to work determined to care. Others *solicit* us, and when we are able to respond, we meet ourselves in them, and they in us.

Melva, an 87-year-old woman who had been abandoned at the ED by her family, bitterly told me how she was cleared by the doctors to go home, but they had been unable to reach her family all day.

> *Melva: Yeah, and, and nobody answers the phone. You see. And uh, some days I eat and some days I don't. See. And I ain't nothin' but, I ain't nothin' but skin and bones now...Because if I thought, if, if they would a cared anything about me, they woulda came today, and they woulda come and seen about me. You see what I mean. [Yeah.] They put me here this mornin', and uh, nobody came back to find out if I was gonna stay, or if I was gonna go. You see. And uh, so, nobody came. So...*
> *Int: That must make you feel pretty bad.*
> *Melva: Huh?*
> *Int: Bad, or mad, that must make you feel pretty bad.*
> *Melva: Yes, ma'am, it did, it, it hurted me. Because, I, because I think of all my nephews 'n', and, uh, I have. I think somebody coulda came back. And see what, uh, and see, Aunt Melva, are they gonna keep you, or if you're gonna stay. Ain't nobody put their foot back to see if I was gonna stay there or not. And when the time come for to dismiss me, nobody couldn't find her. You see. Nobody didn't know where she was. The phone rang, and it, and, and, and rang, and nobody answer the phone. And uh, now you see, I woulda been up there all day without any food. You see, without eatin'.*

Here the ED serves not as a welcomed respite for the patient, but as a dump, resulting in a disheartening confrontation with loneliness, neglect and dependency. Melva had been an ED patient under similar circumstances on a number of previous occasions. In this case, a hospital social worker became involved and a temporary admission was arranged; there was talk of finding an alternative living situation for Melva.

Melva's story was not unique in my study; nurses told me other stories of, for example, seniors who were "dumped" in the ED for the day while the rest of the family moved from one house to another. Such stories point to the vulnerability created by the lack of respite care and community support for families overburdened by multigenerational caregiving in an environment in which economic constraints prevent caregivers from staying home to provide care and community care is unavailable (Estes, Swan, & Associates, 1993; Fulmer, McMahon, Baer-Hines, & Forget, 1992). They also point to the vulnerability of ED care providers, who are being asked to carry out social functions far outstripping their capabilities and resources.

Recognition as Standing With Families

Many times families simply could not cope with the family member who was the "frequent flyer." Sometimes this took the form of refusing to come get the patient when the ED called them for a ride home; occasionally, family members simply stopped answering the telephone or being available at all. Other times, families utilized the ED staff as an intermediary between themselves and the "bad seed" family member who was a "frequent flyer." One nurse told me about her involvement with the family of a patient who, like Matthew in the previous chapter, died at a young age after a long struggle with alcohol dependence:

> *Int: How did you feel about Alex? Did you take care of him a lot?*
> *Nurse: It's funny because his mom came last Monday and I had--I had talked--for some reason I'd developed this rapport with his mother. She lives in [suburban city].*
> *Int: You've talked to her before?*
> *Nurse: Oh, many times. Many times. And she's the type of person, who I think feels a little guilty about what goes on with her son. And she came--she finds one person and focuses on them. So one time when he was admitted to the hospital, I was the charge nurse so she called me pretty much for 12 hours two days in a row. You know, he was up in the ICU--and wanted me to find out this or that. You know, I tried not to play into it for her, but to help her out.*
> *So she came in last Monday and I recognized her and her husband and she said, 'Patty, right?' And I said, yeah. And she said--I said, how's Alex? Because I knew he was upstairs. And she said, 'Well, they turned him off an hour ago and he died.' She said, 'You know, he's brain dead since Thursday or Friday.' They had decided (inaudible) and she said, 'I just wanted to thank all the nurses'--this really surprised me--'all the nurses in the emergency room because he always spoke so highly' of us. And I said,*

> *'Well, that's really nice.' And, you know, you wanted to say something nice about the guy, and I said, 'You know, he, uh, he was a fine person when he was sober.' I said, 'You know, he had a drinking problem and his best didn't come out then.' And she got real teary-eyed. And I said, 'You know, he was a big boy. He was a big boy. He made his own decisions. You know, none of this—it's not your fault.' And she was like, you know, kind of crying. And, I mean, I just, I felt really bad for her, because you know that she felt this tremendous amount of guilt. You know, she couldn't save him. And, which I think everybody wants to do with their kids. You know, to protect 'em and save them.*

Emergency care providers, like Alex's mother, want to "protect and save" the patients for whom they stand in as families, but, like her, they cannot always figure out ways to do so. Here the nurse has acted as a "bridge" between Alex and his family, both during earlier hospitalizations, when she helped the mother interpret Alex's situation, and after his death, when she tries to assuage the mother's guilt, thereby standing with her in her grief. Learning the right place to stand in is a delicate matter of balancing, just as with parenting. It is not a decision between rigid paternalism and autonomous patient choice, though these are often the extremes between which providers feel they must choose.

Learning the right place to stand in as family is, rather, a way of attending to the person's concerns in the particular situation, informed by shared history and understanding. In families, parents decide what to allow children to do based on their situated understanding of their particular child, his or her particular capacities, temperament, and habits, and the context of the situation, not on rules or laws that prescribe permissible behavior for certain age groups and restrict it for others. Providers who appreciate that they are standing in for a patient's family endeavor to achieve a similar understanding, but this is made more difficult by the episodic, abbreviated, and often conflictual nature of their contacts with "frequent flyers" and by the social expectation of universal independence. Often they feel that their efforts are wasted, which is why they are surprised and pleased, as this nurse was, to find they are remembered at all.

The social institutions of medicine and nursing, with their historical delineation as "male" and "female" occupations, function socially as protective parents as well as controllers of deviance (Conrad & Schneider, 1992). While there is a justifiable critique of paternalism, its discrediting seems to have led to an equally unsatisfactory extreme in which patients and families are sometimes essentially abandoned, the assumption being that they are autonomous, rational "consumers" who should best be left to make decisions on their own. This results in situations where patients are morally isolated and medically adrift. The other story beneath this narrative is one about the way our culture views substance dependency as a strictly individual problem, rather than a manifestation of larger social problems such as poverty, anomie, and the disintegration of extended families.

The Possibility of Transformation

A particular kind of recognition practice is revealed in what I call narratives of transformation. This study tapped a rich vein of narratives about patients who once were "frequent flyers" and now were metamorphosed into persons very like the providers themselves. Providers brought these stories out like treasures. These narratives of transformation served to keep alive providers' sense of possibility for even the most apparently hopeless cases.

> *Nurse #1: And the other one was, is Wilford Boucher, and he used to be just another absolute wreck, he'd come in with cellulitis, abscesses, maggots. And originally from [city]. Had a mother here. Uh, I think the story behind this guy was he hit the skids because he made it to like triple A ball and then never made it to the big leagues, is what I heard. And, uh, you know, really down and out, absolutely filthy, would lay down in front of cars. Terrible! Rude, obnoxious, whatever. And who knows what happened. All of a sudden he disappeared. And one day--I'm going to say probably a year and a half later, and it's been years*

> *now—a cab drove up in front of the emergency room on a Saturday and who is it but Monsieur Boucher who had a dental problem. And he was living in [city], [city], something like that. Cleaned up.*
>
> *Nurse #2: [suspiciously] Came all the way here for his tooth?*
>
> *Nurse #1: Well, he had been to see his mother and his tooth flared up. It was a legitimate thing.*
>
> *Int: And he was cleaned up, too?*
>
> *Nurse #1: He was cleaned up, too.*
>
> *Nurse #2: [incredulously] Wilford Boucher?*
>
> *Nurse #1: Wilford Boucher.*
>
> *Nurse #2: Wow, that's fabulous!*
>
> *Nurse #1: Yeah.*
>
> *Nurse #2: You know what's weird? It's like you never know. Are they dead or are they sober?*

That this nurse remembers and tells this story, even years later, is evidence of the way such stories are preserved and retold to remind oneself and other members of the nursing community of the importance of retaining hope. This is an indirect form of recognition practice in that such stories serve as reminders of the personhood that lies buried within even the most repellent and objectified of patients. These stories are moral sources for good practice, helping individual nurses ward off despair and alienation and linking them with the larger narrative tradition of nursing.

> *Nurse #1: And it's like if you don't see them for a while, you think, oh, maybe they're like deceased or something happened to him. We haven't seen him for a while. And every nurse here knows him. It's like, you know, if they sign in, you put them in the [holding area]. It's like, oh, God, now (inaudible) because every nurse knows that he's the most abusive person. Well, one of the most abusive. Anyway, we hadn't seen him for a while.*
>
> *And I was at triage one day and this guy comes up with a book in his hand, and, you know, saying he has back pain. I said, okay; he looks, you know, as if he's had a tough life, but looks clean-shaven and all of the rest. So I asked him to give me their little card to, you know, to speed things up so to get their*

name, and stuff down. So he hands me this card and the name is William Pierce. And I said, no. I said, wait a minute. William was either beaten up or robbed and somebody took this card. And I turned around and said, 'You're not William Pierce.' And he says, 'Yes, I am.' And I said, '<u>You're</u> William Pierce?' I said, 'What happened to you?'

And he was in--he'd been in this program and he looked like a million bucks. He had this book, really like, good book he was reading. And he had back pain. He says, you know, 'When I got all the drugs out of my system, my body starts to hurt. My back hurts.' But he wasn't like actively drug seeking. And he looked fabulous. And he looked like a very --like as if he was an attractive guy at some stage. I mean, he still was kind of attractive but you know....

So I was just amazed. I went back to [another nurse] and couple of others. I said, 'You won't believe this here, William Pierce.' They're like, 'Oh, God, no.' And I said, 'No, no, no. You have to come out and see him!' I said, 'This is like, you know, unbelievable!' And, um, he was so happy that everybody was giving him so much attention, and he was like--you know, he felt so good, and we were all like telling him how he used to be when he came in and, you know. But he--

I saw him about a couple, about maybe a month or so later, back off the wagon. He fell off the wagon again. But he got himself--we haven't seen him in a long, long time. And--

Int: So you think he might have gotten himself back on [stopped drinking], you mean?

Nurse #2: I think he's probably back on because he hasn't been--because this is home. This is where he comes because he gets so out of it, and, you know, this is where he comes. But--

Int: Does he usually come by ambulance, then?

Nurse #2: Oh, yeah, oh, yeah. He can't even walk. He's so drunk, it's like unbelievable. But he used to be--I talked to him one day, I said, you know, "When did you start drinking?' Or I said, 'What caused all these problems?' And he said, 'When I took my first drink.' And I said, 'What age was that?' And he says, 'Eleven.' And I said, you know, 'Where did you work at?' And he worked himself up to a high executive in a communications company and lost it all. Some of these people, you know, really are people that have been functional, and lose it, or some that have never been functional and lose it anyway.

Here a patient who had formerly been viewed as irredeemable presents "with a book." That he holds a book is important to the story, because it is symbolic and practical evidence of just how different this person at the triage desk is from the "out of it" person of his own recent past. Reading requires attention, integration of ideas, memory; it suggests a coherent narrative of self. The nurse is so accustomed to seeing this patient as an objectified, obdurate body, always drunk, largely passive, that she is initially unable even to recognize him physically in this context.

Once she does so, this recognition becomes cause for a shared group event of celebration and a mutual reclaiming of the past. The nurses come out and "tell him how he used to be," and he appears "happy" as he basks in their admiring attention. Now, this celebration says, now we can talk together; now the history we share can be evidence not of failure and despair, but of redemption and community. This is a prodigal son story in which the "frequent flyer," once the antagonist, is welcomed "home" and his return is joyfully proclaimed.

Even a subsequent fall "off the wagon" is seen as forgivable and understandable now. The genuine achievement of abstinence, even if only for a little while, has offered these nurses a window through which they can see the patient as other but not wholly other, not as adversary or burden, but as ally and "member" of the cultural defenses against death and disability. The patient's partial redemption is taken as evidence that their efforts have not been entirely in vain, not mere exercises carried out upon an inert or resistant object. Another nurse talked more explicitly about the differences he notices in alcoholic patients after they have been abstinent, even for a short time:

> *Nurse #1: You know, I just think they're easier to deal with when they, when they-*
> *Int: They're easy to deal with?*
> *Nurse #1: Easier to deal with because they've been like—once they clean out and then they sort of relapse—*

Nurse #2: Well, they get their self-worth back, too--

Nurse #1: They've been through this before. They know the system. They know the routine. It's almost like the fight's within themselves. It's not with the system. It's not with us. It's not with the ER. They come in. They take their clothes off without fighting with you. You know, they let you put the IV in. They let you draw the blood. They usually are not belligerent and hostile and abusive.

Int: This is, this is after they've cleaned up and then fallen back again.

Nurse #1: Fallen back out, right.

Int: That's interesting.

Nurse #1: Yeah, it is. Actually I really think--thinking about the three or four that I can think of right off the top of my head. Um, they are a lot nicer now than they were the first time they were frequent flyers.

Nurse #2: Well, I think it's 'cause they have a better sense of--like they know the only one to blame is themselves. It's not--I think when you're in an addictive state or, you know, when you're in your addiction, you have a tendency to blame everything around you for where you are.

Nurse #1: Yeah.

Nurse #2: And then when you clean up and, you know, you go through rehab and you get this sense of, you know, you know, it's only me. You know, I'm to blame. I think that's what makes it easier when they come back because they know it's not, you know, it's not any external things that have put them there. It's themselves.

Nurse #1: They get--

Nurse #2: And I think they're more at peace with that kind of thing, you know what I mean?

Nurse #1: They get programmed, you know, because most of them go to 12 step programs and they get that whole thing about responsibility and, you know, and some step work in there. So they, they'll say, you know, I had 2 years and I blew it, you know. (Mhm) And there's a lot of humility there, I think, as well as, um, humiliation. You know, so--

Int: What, when they break down?

Nurse #1: Yeah. And it's almost like I think, you know, I guess the 12-step term is like they're retreads, you know. I'd almost rather take care of a frequent flyer retread (laughs) than an original frequent flyer because you can kind of help--to

> *me, there's an impact. You can make an impact, you know, and give them their encouragement. They know what it's like to have been cleaned up.*

In light of the apparent failures of the "system" to help these patients, this nurse can only attribute the change in such patients to individual shouldering of responsibility, revealing the social embeddedness of a perspective in which personal responsibility is understood as both cause and cure. Yet, paradoxically, this attribution seems to promote in the nurse a more forgiving attitude, even perhaps a kind of absolution from blameworthiness (Conrad & Schneider, 1992; Lowenberg, 1989). There is an acceptance of the patient that, as this nurse admits, is harder to achieve with "original frequent flyers." How is this to be interpreted?

One interpretation might suggest that absolution is granted on the basis of the patient's acceptance of the provider's explanatory model of illness (Kleinman, Eisenberg, & Good, 1978) or his submission to the provider's will. In power terms, the patient is now showing evidence of "compliance," thus minimizing his illegitimacy; the authority of providers to define the problem is respected, not resisted, and thus it is easier to care for the patient. When the provider meets no resistance, the patient is less a threat to medical control of his own body, the department and the larger social order.

The same situation may be interpreted rather differently from a perspective of care and connectedness. As discussed earlier, patients and providers are often unable to recognize one another and are drawn into adversarial stances, yet, for both, such a posture is inherently unsatisfying. Providers long to feel part of helping, and patients long to feel understood. An episode of sobriety, even if it is temporary, allows both of these to occur, if only briefly: patients are acknowledged as actively engaged in the struggle to save themselves, even if they often--or ultimately--fail, and providers are recognized as being on the same "side" in that struggle, even if their contributions are limited or unclear.

Issues of blame lose their relevance when the "end" is a relationship based on care, rather than an "outcome" predicated on control and questionable "cure."

Which interpretation is the "truer" one? I would suggest that the latter is the more practically useful and morally justifiable. The former perpetuates the dominance and submission that, as Benjamin (1988) notes, accompany our cultural fear of individual helplessness. The latter moves us toward an acknowledgement of our mutual interdependence upon one another and an understanding that when "cure" is elusive, "healing" or simply understanding may be worthier ends.

Troubling Transformation Narratives

Sometimes the stories of transformation did not have "happy endings."

> *Nurse: I felt bad when Steven died. I--I took that home. It bothered me for awhile.*
> *Int: What? Tell me about that.*
> *Nurse: Steven was a guy that used to come in all the time mostly because he was drunk. He'd come in between the hours of like midnight and 2 in the morning.*
> *Nurse #2: And again, he'd been coming in for probably 15, 20 years.*
> *Nurse: And he had seizures so, uh, and he had a legitimate reason to come in. He would take his medications and then he'd start drinking, and then he'd stop taking his medications and then he would seize. And so he used to be in all the time. And uh, one night in particular he came in because he said he had stopped drinking and he was going through DTs[delirium tremens], or stopped drinking and he needed some help and he had the shakes and--I put him in a room down over in the Pediatrics side. I went out and got the doctor and she went back down there and said, 'He's going through the DTs. How could you be so stupid, putting him down there? Get him up into a bed where we can keep an eye on him.' So I go down; he's not in the room. He's down in another room, laying on the floor, picking spiders off of the walls. I took him in the room, put an IV and draw his labs, admitted him for going through DTs. He's got a blood alcohol of 342...*

Later, the nurse says, Steven came back in clean, sober, with a girlfriend:

> *Nurse: He came in and he's got a sparkle in his eye and he looked good and he didn't stink. And uh, he looked like he was starting to get his life back together. He was only like 36, 37. He came in for seizures, and I gave him his Dilantin and, you know, they admitted him because he also had like a pneumonia--he was in room 14. We moved him out of room 8 over to 14 so we could monitor him on the monitor while we IV'd his Dilantin into him, and after that, I took him off the monitor, had him all packaged to send to the floor. Five minutes later, his girlfriend comes out, 'help, help, help.' Steven died. He just kind of went into a respiratory arrest and followed it up with V-tach--he, basically, he was dying in front of us. And nobody caught it, picked up on it. It was very sudden. He came in. He wasn't tachypneic, he wasn't--. He didn't have--his vital signs were stable when he got to us. It was very sudden. And it bothered me because people just aren't supposed to do that. And here's somebody who I was just about ready to flush down the toilet...*

For this nurse, there will probably always be something discomfiting about remembering Steven. There is an underlying worry expressed here that the nurse's clinical sensibility about this patient somehow failed on two occasions. The first story is told as evidence of how Steven could be tricky to assess; the doctor is convinced Steven is in alcohol withdrawal, but he turns out to have an elevated blood alcohol level after all. In the second story, Steven dies without warning, but the nurse seems to wonder if there wasn't perhaps something that should have been noticed. The tragedy of finally getting one's life together, fending off the specter of death and then having it come and sneak up on you in the ED, where you are supposed to be safe, where you come to be rescued--this is disturbing. It challenges the tacit assumption that once these patients get their lives together, their problems will be over. Such a situation calls into question the social ordering whereby individual self-responsibility is thought to be rewarded with bodily health and brings the limits of individual control into sharp relief. Even personal transformation, it seems, cannot save us.

CHAPTER NINE

THE LONGING FOR BELONGING: GLIMPSES OF COMMUNITY

Nurse: But, uh, but most of the night people are, haven't been here very long, so they don't know the real old timers. But the real old timers used to use this facility as a, uh, social drop off, I think when they were frightened. When they were--they didn't have anything better to do, or they didn't know how to get home, or they weren't allowed to go home, or whatever the reason was; we never really did find that out. But they would drop in.

Patient: I don't say one should have, and the other one shouldn't. Have help. And if I have a little bit less to help some child that don't have none...I'd, I'd rather do that. You see what I'm saying?
Int: You think most people feel that way?
Patient: I think, well, if they don't, they--well, you know, it's a sad world, I don't think most people--I think most people are a bunch of selfish people, but then, I think that's what's wrong with the country now, so, you know what I mean?
Int: Yeah, I agree.
Patient: Everybody trying to get over on everybody else. But we're not goin' nowhere, are we? We're not even goin' nowhere as a world no more.

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Introduction: The Problem of Community

This chapter begins the transition from the level of patient and provider experience emphasized in the last three chapters toward the larger issues which bear directly on that experience. The "problem" of heavy users of emergency services, as the previous chapters reveal, is not merely a problem of individuals who choose to obtain their medical care from the wrong place too often, or fail to follow instructions. Nor is it merely a problem invented by medical providers who dislike caring for certain types of people. It is not merely a problem of lack of public health programs, though their lack has clearly been a contributor; nor is it only a problem of economic or civil inequalities. It is, however, a bellwether of all these and more. It is a problem with broad social meanings; it is both created and maintained by our cultural difficulties with dependency, and it clearly involves many players outside the ED itself. At its root, it is a problem of community.

Communities, as Benner (1991) has pointed out, "are not inherently good, but they are the only places where the good can be instantiated and worked out" (p. 16). This is because communities are constituted by practices of commitment to others (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1985), practices not based on economic exchange, but on traditions, hopes, history, and memories. Hospitals are themselves communities, of a kind, as we were reminded by the social worker in Chapter Three, and EDs are microcommunities within them. But, as the participants in this study made clear, such smaller communities are struggling to maintain themselves in the face of massive pressures to redefine themselves as strictly business enterprises.

Hospitals as Caring Communities

American hospitals have a long tradition of caring for the sick and the poor, beginning with their eighteenth-century almshouse origins (Rothman, 1990, Stevens, 1982, 1989). Almshouses were established as receptacles for the indigent and dependent, but as Rosenberg (1987) points out, by the late eighteenth century, the almshouse had "become in part a municipal hospital in function if not in name" (p. 4). The two institutions were at this time often indistinct from one another; in some larger cities, a separate ward housed the sick from "the simply destitute, the orphaned, the marginally criminal, and the permanently incapacitated who also populated this warehouse for the dependent" (Rosenberg, 1987, p. 4). The population of "frequent flyers" today bears a strong resemblance to this almshouse population, as should by now be evident.

Lest the reader assume a kind of romanticization of the past is implied by this association, let me emphasize that how "caring" these institutions were is questionable; they were notorious for housing society's rejects, and they were shunned by "respectable" people until the late nineteenth century, when the "modern" hospital was born (Dieckmann, 1993; Rosenberg, 1987). But the almshouse, and subsequently the modern hospital, always carried out a socially prescribed role in providing services that could not be considered "medical" in a narrow sense--shelter, food, protection, general aid and referral, and, in some way--albeit sometimes temporarily and inadequately--a community for those who had no other. These institutions also reflected and reproduced the social relationships and concerns of the larger community. This chapter will focus on the ways these broader social functions are and are not today still carried out by hospitals, and particularly by emergency departments, and on the ways these caring communities are threatened by larger social forces.

Paradigm Case: Mike

> *A lot of people'll come in that waiting room, they go, 'Hey, Mike!' ; everybody in the waiting room knows me. That's for sure, you know. The new people that sleep in there, you know, they know me, they know <u>my</u> name. I mean, they kind of know that I'm, I'm like the captain of the ship.*

Mike is a 42 year old man who, according to the doctor who introduced us, "lives in the lobby of City Hospital." I first encountered Mike when, during a day of ED observations, I noticed the doctor speaking loudly and rather heatedly to this man in the hallway. "If you don't care about yourself," I overheard her saying, "How do you expect other people to care about you?" Spotting me, and knowing of my interest in studying frequent visitors, she grabbed me by the arm and led me over to where Mike still stood waiting.

She later told me she felt frustrated and overwhelmed. "You don't know how it is," she told me. "Because City Hospital presents itself as able to handle all these problems, but you know what? We don't even come close. What can we do for these patients?" she asked, almost desperately. Her frustration stemmed from her review of Mike's medical record, which revealed that Mike had made multiple visits to the ED with rather atypical "seizures" and had been given prescriptions for antiseizure medication, but he had never kept any of his follow-up appointments to be evaluated in neurology clinic. She refused to refill the prescription for him and insisted that he had to have a neurology evaluation. "He wasn't mad when I told him I wouldn't refill his Dilantin, or anything; he just really seemed like he was glad to talk to me," she added, somewhat bewilderedly.

Mike was well-dressed, clean and groomed; he did not have the appearance of the typical "street person" often seen in the lobby of City Hospital. He was quite amenable to talking with me and came across as friendly, cooperative, and open. I interviewed Mike twice; the second interview was conducted about two weeks after the first. Riding in the elevator on the first occasion to a place where we could talk quietly, Mike said to me that this doctor was very caring, but he thought she was getting mad at him because of the missed appointments.

> *She's getting a little upset about it. I know that. I'm worried about this problem that I've been goin', and follow up with this appointment, and I haven't done it. So that's what she's tryin'--she can't figure that out, you know. Why am I doing this to her? I really don't know my damn self.*

Mike has been homeless for about six months. He lives on an SSI check of approximately $600 monthly. At one time, Mike says, he was employed as a head custodian for another hospital in the area.

> *Mike: I worked there for about seven years. Uh, I was the head custodian. I was housekeepin' out there. Uh, then I worked a couple of places here and there. I've worked all my life. I've never been no bum. Um, and then, you know, I started drinking heavy and started getting in trouble. That's kind of how I lost my job at [hospital]. I loved that place, too. And I'm drinkin' and being late and not coming in on time and stuff like that. Called in sick, lyin', they knew. They caught on after awhile, and they let me go. And uh, you know, then I started goin' downhill from there.*

Because Mike seemed very articulate, I asked him about his education. He graduated from high school, he said, and has "a couple" years of college.

> *Mike: I just let it all go down, it's, it's, I'm a complete idiot, hey. It's such a waste.*
> *Int: What happened this last time that--I mean, I'm just sort of interested in this because it sounds like you were working all your life before and you've pretty much at least had a place to live and then now you're homeless and you're not working and what's, uh, what was it? Was there anything in particular that you think caused that shift?*
> *Mike: Well, a lot of little things. Uh, lost a girlfriend. Uh, (pause) I don't know. I just, I was havin' problems with my girlfriend, that's number one. This particular girlfriend. And uh, you know, I done gave up on that. Uh, then I lost my Mom. I lost my Dad. They both passed away. You know, that, that hurt me. That one really got me because my Mom, that was my sweetheart. I was close to that lady. I mean, I got a big family. I got 7 brothers and 7 sisters. Same mother, same father. There's 15 of us. 8 boys, 7 girls. And out of 15, I'm the only one that was fortunate enough, as far as I'm concerned, to be born on her birthday. Like this year comin' up, is going to be the first birthday of my life that I'm going to spend without her. That's going to be a trip. See.*

Mike was with his mother when she died, he told me; he was sitting at her hospital bedside reading to her when he looked up and realized something was wrong.

> *Then I said, could somebody check my mother, uh--something's not right here. And so they got to checkin' and they (inaudible) and next thing you know a whole bunch of other people come runnin' in there, and--(pause; emotional) I just, ah! I take a deep breath, I knew something with her wasn't right. And then they come over at me and they go like, 'Your Mom's gone,' like that. And I went, oh, shit, I couldn't take it. And, and I just, I left, I walked out of that hospital--you know where [hospital]'s at. I walked from there, straight down the street to the river. I mean, I walked all that way, and I went, and I sat on that bank and I just stared at that water. I--and she, she died about 12:30 in the daytime and I'd say I got down to the river at about 1:30, I guess, you know, and uh, I stayed on that bank until almost the very next day at that time. Yeah, I sat there that long. Just on that riverbank, just sit there and looked. I don't know why, I been trippin' on it, just watchin' the water.*

One senses that Mike also walked out of the world when he left the hospital, as he goes on to describe picking up a pattern of heavy drinking and drug use after this:

> *Uh, somebody after that [said], 'Uh, condolences on your Mom and Dad, man, can I get you a drink?' --you know. Of course you can, and this goes on and on and on.*

Mike says he has brothers and sisters in the area. I ask him if he is close to them and he replies,

> *Mike: I'm close to 'em but I'm, I'm uh, let's see, how do I put this here. (pause) They don't want, they don't like seein' me like this, and they want to help me the best way they can, but I won't let 'em.*
> *Int: You mean, to get off the crack and--*
> *Mike: Yeah, well, that and to, to get my life back together and get my own place and not be homeless and don't be on the streets and shit. 'Cause I have too much family to where I have to be on the streets. And I'm well aware of that. But, and they--but I won't let them help me.*

Over the past year, Mike has made over 50 visits to the ED. And, as the doctor said, he has "lived" in the lobby of the ED for several periods, once as long as a month and a half by his own estimate. He also mentions that he has sometimes stayed at city homeless shelters, but says he prefers the ED lobby because

> *Mike: I get treated better. In those--in those places you got people that, uh, you got the type of, all types of people in those places. You know, you have folks that are crazy, crazy. You know, I'm not talking about those that are just havin' seizures and stuff like me. I'm talkin' about those that are just* <u>*crazy*</u>*. You don't know* <u>*who*</u> *you're sleepin' with. ...I mean, I've seen, I've seen some pretty horrible things out there, you know, um. I don't want nobody comin' and choppin' up my sleeping bag in the middle of the night, you know, so, it's kind of crazy. It's not--some people don't care about that. I do. You know, it's not that I'm afraid of life because I'm just as crazy as the next man out there as far as I'm concerned. But still I don't want it to happen to me, you know. I know what I've seen. I've seen people just go off for whatever reason. And, and, like, you know, like I said you don't know who you're sleepin' with. You know, you could be sleepin' with the Zodiac. You all don't know. You end up--you can't tell who you're sleepin' with.*
> *Int: Of course, the Zodiac could be in the ED lobby, I suppose.*
> *Mike: He could be, but at least I'll be closer to a doctor.*

This issue of safety came up in many of the interviews I conducted, but it was Mike who helped me see the link between simple physical safety and a deeper kind of psychological safety and security that a familiar place provides those who are recognized as belonging there. Safety and security, in this deeper sense, are associated with the experience of home, a place where strangers stand out, family are never turned away, and one can let down one's guard.

> *Mike: The security guard, now, those security, like my partner there,* [gesturing to a security guard passing the table where we are talking] *those security guards know so many different people, like myself, and once they see a strange face hangin' around for awhile, they're gonna check him. See. So it's like right, right here, I'm at home...It's a bad way of puttin' it.*

> *But uh, I'm, I'm, I feel comfortable here. Uh, back at that shelter, man, there's no security guard, not even a guard.*

Mike, having no private home of his own, has through his own efforts and what I came to discover was an underground network of caregivers operating within the larger structure of formal caregiving, established a sense of place--a kind of extremely marginal 'home'--at City Hospital.

Mike's relationship with the ED and with City Hospital as an institution is clearly not an outside-in one. Over and over throughout our conversations, Mike emphasized his "insider" status. He pointed out a security policeman to me and alluded to him several times during our interview, getting up and joking with this man, who was about his own age, during our interview time. He struck up a conversation with an X-ray technician in the elevator, and they both ended up laughing and talking about their experiences growing up in the rural South. Mike does not experience himself as "another patient" but as someone who knows his way around and is cared for and respected by others in the institution. Like many others among the patients I interviewed, he is also intensely loyal to the institution of City Hospital.

> *Mike: Well, okay, you take a place like City Hospital. You don't have to have insurance to come to City Hospital. You know, this is why a lot of people do come...Now, take a person like myself, I've got a brand new* [Medicaid] *card, I've got Medicare, I've got Blue Cross. And I still come to City. I can go to any hospital I want to.*
> *Int: How do you have Blue Cross?*
> *Mike: I don't know, but they gave it to me.*
> *Int: And you can go to any hospital you want to?*
> *Mike: I can go to any hospital I choose to. And the only one I come to is this one, you know...Like I, in fact, give you a good example, I had a, uh, I had a seizure right in front of [other hospital] and they took me in there and I told them I wanted to come to City. And that probably tripped 'em out, you know. That's when, that's when I found out that I can do anything*

> *with that, with that card. 'Cause they said, 'well, you got Medicare, you could stay here, it's okay.' I said, 'I don't want to stay here. I want to go to City.'*
> *Int: Do you think most people feel that way?*
> *Mike: Uh, I doubt it. Just I know I do. You know, I couldn't, I couldn't tell you how other people feel about it. Um, I've seen--I think there's some other hospital waiting rooms that <u>looks</u> better than this one. But so what? I, I still, I'm, I'm <u>comfortable</u> here. I been here so many times. They've done so many things with me, what the hell, I wouldn't give 'em up, you know. And I wouldn't know why--A lot of people say that. I feel safe here.*

He amplified this praise a few minutes later, noting that he saw some people from another part of town out in the waiting room a few minutes before.

> *And right there they can go to [lists several other hospitals in that area of town], and they come here, you know. Why is that? 'Cause they feel better here. It's a good place.*

The institution of City Hospital, in Mike's world, is a kind of protective moral space, a place in which goodness is made visible in practical activity and in which one can in some sense participate in that activity. This is made clearer when Mike talks about how he has seen the staff drop everything to do lifesaving work.

> *Mike: It's good to know--because that could happen to me, you know, and they're good. They'll drop everything and get at me. You know, I've seen them do it. And the way they go at it, it's like, it make me feel good to be sittin' here, you know.*
> *Int: So you see them do that while you're over there waiting for something else...*
> *Mike: Yeah. Yup. I mean, I've seen them push me aside for something like that, which I don't mind because I already know what I'm here for, I'm not gonna die, you know, so you handle--get that man, or get that girl over there. ...You know, that's good to know for a person that's not drunk, uh, on crack, or anything, that just happened to be sittin' here and happened to see this...*

> *Int: What do you mean, not drunk or on crack? You mean if they were drunk they wouldn't sort of get the--*
> *Mike: It's like if I was drunk or whatever, 'n'trippin', and I seen how these people ran to help out somebody, I wouldn't give a shit. But I actually get to see this here, how they actually work, and I know it's all good here, and I like what I see.*

Here Mike watches, not merely as a passive observer of activity, but as an engaged participant as he mentally facilitates the work by his cooperation and feels a thrill in being part of a larger work of public goodness. When he says, "that's good to know" he seems to suggest that being part of all this heroic, lifesaving work, even as a bystander, may be good for him personally. Just by being present, he feels in some way associated with work he unambiguously defines as good.[10]

If the institution is a source of goodness in Mike's world, it is also, in a very real way, a source of identity as he struggles to reconstruct a life, to reconnect with an earlier self. Mike was not the only one of these patient-participants who pulled from his pocket a packet of "blue sheets," the discharge instruction sheets given by ED staff to patients at the end of each visit. I ask him if anything stands out in his mind about his experiences in the ED.

> *Mike: Um--. (pause) The only--This emergency room, I'm, I'm glad it's here. They've helped me a lot. They saved my ass I don't know how many times. I don't know if I showed you last time. I got a pocketful of blue sheets. You know, I mean, like this--these are all different ambulance rides back and forth here, you know (pulls out handful of papers). You know, these--I mean, it's uh, these are all, this is <u>me</u> here.*

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[10] Stevens (1986) has pointed out that in the United States, all nonfederal acute care hospitals are known as "community hospitals," a term promulgated by the American Hospital Association and one which suggests "creative, local...activities, such as volunteer fire departments, school boards, or the PTA; they are part of the American cultural tradition...Part of the attachment of the word *community* to hospitals thus reflects vague assumptions of the public good" (pp. 87-88).

These sheets are stamped with the patient's name and medical record number, and in Mike's case, as with most of these patients, they include briefly-worded admonitions from the discharging resident physician to stop drinking alcohol, stop smoking crack, etc. Yet even though Mike typically appears to ignore these instructions, (thus marking himself out for providers as a "noncompliant" patient), the sheets seem to serve as a kind of valued record of existence for him. He keeps them and he displays them to me as evidence. The blue sheets remind him that he was worth caring for; they serve as documentation, identification, a kind of diary of a life in which there are few other sources of continuity. When seizures or substance use interrupt Mike's temporal flow, the blue sheets help fill in the gaps.

Life on the streets requires the cultivation of a persona of obscurity in order to survive. Most of these patients have stories about how they try hard not to be noticed. Standing out too much puts one at risk of arrest, assault, or other disruptions, yet there is a way in which we are hardly ourselves if no one recognizes us, as Buddy's story reminds us (Chapter Eight). In City Hospital, Mike finds that recognition in a place in which it is safe for him to relax the constant vigilance that street life requires. Those who care for him allow him to see himself as someone worthy of being "saved."

This is not true in all hospitals, however. In the second interview, Mike confides to me that he sometimes goes to other hospital waiting rooms to pass the time.

> *Int: And I mean, you can just sort of hang out there? They don't kick you out?*
> *Mike: Well, they do once they catch on that you, that's just what you're doing, you know. They figure [if] you're in the waiting room waiting on somebody, then that's fine. But if they know that you're just there to be there, then you're outta there.*
> *Int: But you can usually get away with it for awhile.*

> *Mike: Yeah. You don't want--you don't want to look nobody directly in the eye, and that way, if you keep lookin' at me, and keep noticing, you ain't gonna go, 'you know, you, you've been here the last couple of days. You got to go,' you know. So after awhile, you just, if you can help it, uh, don't even look at nobody, you know.*

This experience of trying to hide in a public space is contrasted with the way he feels at City Hospital, where, though he may engage in some of the same practices to "pass" and be permitted to stay in the waiting room, he is known and respected by some of those in authority. Mike has been told to leave the City Hospital ED lobby, too, but he returns. He is known here. Being known, in the context of a life which outside seems characterized by concealment and rootlessness, carries a profound value for Mike, as evidenced by the many stories Mike tells about his familiarity with City Hospital and the people there.

> *Mike: If I go to that desk there, guaranteed if I go to that window [ED triage window], and you go there with me, and when I go to that window...I'll stand up there in line, then when it's my turn to get up there, I bet someone'll go, 'Okay, Mike, what can we do you for?' Just like that.*
> *Int: 'Cause they recognize you.*
> *Mike: I've, I've came, I've been here so many times! Not just sleepin' in that room [ED lobby] but I'm talking about from the ambulance and from, you know, from legit time. And they'll go, 'Oh, how ya doin' today, Mike? What can we help you--' ...I can go up on one of these floors, and they know me there, you know. It's 'How you feelin' today,' you know? 'You gonna be okay?' It's--'I hope so.'*
> *Int: Do you know them, too? Do you know their names?*
> *Mike: I don't know their <u>names</u>. But uh, some of 'em I know their names. But I know their faces, you know. And like even the guards, they're jokin' with me and, in fact, there's this one guard, he calls me the Mayor of City Hospital...He goes, 'This is the Mayor of the waiting room; this is the mayor of the hospital.' He's really, he's a real tall black cop, uh, good lookin' guy, too, man; nice smile,--and he's, he's very funny. And he tells*

> *all the cops, 'Yeah, that's the Mayor right there.' That's, yeah, and that's all he does. He just calls me the Mayor of the waiting room. The Mayor outside there. He goes--like he'll come to work, then he'll go, 'How has it been here, Mayor?' 'Ah, it's been all right.' You know, 'Any fights, anything bad?' I go, 'No, everything's been nice and calm. You just, you just get out of here.'*
>
> *Int: So, I guess he doesn't kick you out, huh? He kind of...*
>
> *Mike: Well, he haven't in a long time, but he did, uh, a couple of nights ago for the first time in a long time. But it was like he was in a position to where he <u>had</u> to.*
>
> *Int: 'Cause they were cracking down on everybody?*
>
> *Mike: Yeah, see, so dogmatically, now, if he let the Mayor stay, you know, this would be his favorite, you know, he better not do--so then he like, he <u>had</u> to. I could tell he didn't want to.*

The experience of being given an affectionate nickname and identity is one of genuine acceptance as a member of a group, as someone who has a role to play. In conferring this tongue-in-cheek title, the guard is recognizing Mike as an individual, not just another patient; he meets him as another human being (See Chapter Eight). He is allowing Mike to show up as unique and, even though both recognize that the rules still hold and the title is meant to be humorous, he is permitting them both to share the intimacy of an "inside joke." Mike's participation in the joke is crucial evidence that he experiences himself, and is experienced by others, as part of the group. Imagine how different this might be if Mike ignored the guard or became hostile. Instead, he takes on the role with a certain pride.

He also acknowledges the "illegitimacy" of his stays in the waiting room, suggesting that his familiarity and acceptance come from "legit time." Mike thus reveals that he has taken up and understands "official" problems-- those biomedically authorized, or medicalized--as legitimate, and social problems--lack of housing or jobs, loneliness, the difficulties of trying to re-connect after a long plunge into drugs or alcohol--as less so.

Many of the patients I interviewed expressed similar notions; this belies the idea that heavy use of emergency services is merely a problem of "patient education" as to more "appropriate" sources of care. These patients commonly know that their problems are unlikely to be considered "legit," yet they are still problems for them; more "appropriate" resources, further, are often absent or inaccessible.

Mike is even willing to prolong suffering in order to stay at City Hospital, as revealed below, where he is discussing a painful spot where a wisdom tooth was removed earlier in the week:

> *Mike: This one here is killing me right now. There's no tooth there and I'm dying. Right at this very minute. It's uh, my jaw hurt, my ear hurts, my teeth hurt. Everything, everything on this side. Everything on this side hurts right now. You know, so I was sittin' there, I said, 'Well, I should go on and see a doctor, man,' 'cause of the, you know, pain. And I said, 'No, I think maybe I'll wait 'til later.' See how much pain I could take. I'm-a wait 'til later. And that way, the later I set up to see a doctor the longer my yellow band will work for me, you know, in case somethin' happens, I, you know. I expect if I go and see a doctor at um, midnight tonight then my, my yellow band'll be good for all day tomorrow...So I can stay there until 12:01 the next day, you know, so, because I want some rest, man.*

The "yellow band" to which Mike refers is an identification wristband placed on patients who have registered for treatment in the ED. The bands are checked by the clinical staff to verify the identity of patients when leaving the department for tests, etc. The security staff also use these bands as a way to check whether or not people in the waiting room have a reason to be there; if they have no current yellow band, they are asked to give the name of the person they are waiting for, and if they cannot do so, they are asked to leave the premises. Thus, for people like Mike, who hope to rest and/or socialize in the lobby, the yellow band is like a boarding pass, a ticket permitting them to nap safely in a warm (if not quiet) place.

Elsewhere Mike talks about how food has been brought to him or mysteriously left for him by caring persons on occasion, and how others seem to recognize him and say hello.

> *Mike: There are some people that pass by me and go, 'How ya doin', Mike?' I go, (weakly, in an unsure tone) 'Hi.' I don't know how the hell they know me. I don't know them. But it's like, 'Oh, I'm doin' fine.' You know. 'Anything else you want to know?' You know, they know so much about me, but I don't--you know, I don't know who these folks are. But it's all to the good, so I'm--'Okay.'*

It was through talking with Mike that I became aware of a whole underground network of care that seems to center around the ED lobby. For example, Mike told me that while he sometimes would "eat off the belt" in the cafeteria (taking food left on the plates of cafeteria customers as the trays went back into the kitchen on the conveyor belt), worrying all the while that he could get sick from eating something left on a sick person's plate, there were also times that people came to the ED waiting area and simply asked if anyone was hungry, bringing food. I asked him to tell me more about this.

> *Mike: I have one lady. And you have--okay, there's certain people that pick their own people.*
> *Int: Uh-huh. People that they know?*
> *Mike: Yeah. That one--one old lady that works here...<u>she always comes and looks for me</u>.*
> *Int: Really?*
> *Mike: Yeah. She's a little older lady. And I'd be watchin' TV [in the ED lobby] and she makes this little coo-coo sound, like. I'll look--sometimes she wakes me up. I'll be asleep. And she takes me out to the car and she gives me loads of goodies! And it be so much to where <u>I</u> come in there and I'll go, 'Anybody want somethin' to eat?' You know, <u>I'm</u> givin' out a bunch of stuff, you know. Because it's just too--she knows, she have, probably have an idea I'm going to do this anyway. But at least, I get first choice at*

> *it. And it be some good food. Like it's stuff I seen them have during the daytime? I'll look, and--there it is. It's like, oh, <u>that's</u> where it goes. She gets it and they can get it and take it home. And, uh, like the barbecued chicken. One day she brought me a bunch of barbecued chicken. Brought me a bunch of meat loaf. And I took it down there [to the ED lobby] and now there's some guys down there that waits for <u>me</u>!*

This story bears similarity to Sam's story of how Joe gives him both food for himself and the opportunity to share it with the birds. Mike has established himself as a link in an oddly-fashioned chain of informal, underground caregivers. It is striking that it is so surreptitiously carried on; the woman gives a mysterious signal that he recognizes, a kind of secret code, and he goes outside to pick up the food she is delivering. This woman might be at risk for being disciplined or even fired if it were known she gave food to the hungry in the ED lobby. Mike also makes reference to others who engage in this practice, suggesting that his is not an isolated case, and my observation time in the lobby was also marked by more than one food sharing event with different people contributing the food each time.

In another story, Mike tells about helping out someone who was selling jewelry at a table one day in a hallway of the hospital, an activity which enabled him to give back something to the woman who helps him.

> *Mike: They was sellin' stuff. I was helpin' this guy out. He gave me a couple crosses, you know. Real nice ones.*
> *Int: You were helping him sell his stuff, you mean?*
> *Mike: Yeah! You know. Well, kind of not like having me sell 'em but I was watchin' his tables so nobody take nothin'. And uh, he gave me, let me pick a couple of crosses that I wanted. Like about 3 or 4. Maybe it's like thirty, forty dollars apiece. And I seen her [the woman who brings him food from the cafeteria] and I go, 'hey, I got something for you!' You know, and I gave her a couple of 'em, you know. Still had the price tag. She goes, 'I have no money--' I said, 'I didn't ask for no money. Here.' She goes, 'Oh,*

> *my daughter's gonna love this here,' you know. She was just so happy to get this, right? And she goes, you shouldn't--I said, uh, look, just get away. I don't want, I don't want no money. Leave me alone, you know. And she was so pleased to get these little crosses here...And she goes, keep one, and I go no, as long as I got my--(gestures to pendant he wears) you know, I had this thing here for a long time. As long as I got that, I'm, I'm fine. Well, she was so pleased with that. And I said, here I got one more. Take this one, too, I don't need that one neither. Cause I mean, at one point in time, I might have kept it in my pocket. Moms would have got that. You know, but--Moms is gone, damn it.*

That this gesture goes beyond mere reciprocity, mere exchange, is suggested by the way Mike links this gift giving with his memories of his mother. The institution and its formal and informal networks of care and concern offer Mike and others like him a kind of replication of family relationships. The commitments here are fluid, allowing him to set a level of involvement that fits with his level of trust, and yet he is reassured that there are basic expectations of conduct and boundaries of behavior that will be enforced.

There is, however, variation in how the behavioral boundaries are enforced in actual practice, as Mike reveals in a discussion of his experiences with the ED nurses at City Hospital:

> *Mike: They're, they're, they're cool, they're friendly, you know. Uh, they know how to calm your ass down.*
> *Int: Know how to calm you down?*
> *Mike: Yeah.*
> *Int: Like what?*
> *Mike: I mean, if you bein' silly and, and, and loud, and stupid, they don't act silly and loud back with you. They just kind of cater to your ignorancy and let you go on with it. And uh, you know...I've seen how they do it. It's pretty good.*
> *Int: What do you mean they cater to you?*

Mike: Well, they kind of are like okay, you bein' this asshole, they--'Hey you bitch, you this and this,' and they go, 'Yeah, okay, okay, you're right, that's fine.'

Int: They kind of humor you...

Mike: Yeah, or they don't get all upset like, 'Well, if you gonna call me a name, I'm not gonna work on you.' Man, they just say, 'Okay, well, why don't you let this bitch take your temperature here,' or somethin' like that, you know....It's pretty good. To be able to deal with the, with the idiots at the same time, that they can do that. That's cool. I don't know if that comes along with their training but they do that pretty well, you know. I mean, uh, reason being is--I've been an asshole, and I've had a few of 'em come like that at me. You know, I say, 'God damn it, why don't you leave me alone?' And they go, 'Okay, we'll leave you alone just as soon as I take this temperature, okay?' Or they say, 'We'll leave you alone just as soon as we find out your blood pressure. But up until then, we're not leaving you alone, pal. We're gonna save your life,' you know. You know, hey. So it's like you're mad, but you can't be too mad at them because they're sayin', well, you know, in so many words, shut up and let me put this thing on you! (laughs) You know, but they're doin' it in a good way, so--

Int: Have you ever seen them lose it?

Mike: Uh. (long pause). There was one, I think. I don't know if she was a doctor or a nurse. She's here now, as a matter of fact. I don't like her. But it was me being the rude, you know, I was being the asshole, no doubt. And she took it as long as she could, I guess, and then she finally told me, 'Why don't you shut up!' You know, like that, and I go, 'Uh, you talkin' to me?' And she said, 'Yes, I'm talkin' to you!' And you know, next thing I know, I shut up. 'Cause I guess I wasn't used to it. You know, I wasn't used to someone tellin' me, why don't you shut your mouth, you know? And I guess she took it, as much as she could take, heh-heh! and finally I shut up. I didn't think I would, but I did.

Int: Must have been pretty authoritative, huh?

Mike: Yeah. And she's not no--little chick, neither. You know, seemed like the type, if you don't shut up, I'm gonna shut you up. You know, it's like--'Okay.' Or if I've been talkin' back to her, now I'm not talkin' back as loud no more. It's like, (softly) 'Yeah, I don't have to shut up if I don't want to.'

> *You know. Like under my breath now. 'You don't scare me with what you did.'*
> *Int: But you don't like her all that well, huh?*
> *Mike: No, because she, she, she beat me up with her--authority...I don't hate her though but it's uh, she won, and I didn't want her to win.*

In the first version, the nurses are seen as affectionate, parental figures who indulge a favored child, displaying caring even when he misbehaves. They gently affirm his worth and ignore his failures. In the second, the nurse is a critical, harsh parent who uses her authority in a way that he perceives as abusive. The relationship is adversarial, unequal, and threatening, an affront to Mike's understanding of the institution as embodying goodness and security. Even so, he makes an effort to understand the nurse, blaming his own bad conduct that pushed her too far.

This parental aspect of the institution itself is suggested by another response Mike gives when I ask him if he can think of anything that could be done to make things better for patients at City Hospital:

> *Mike: What they have to do? They already got 'em spoiled. They got me spoiled. I mean, I don't know; what else would they need to do?*
> *Int: How do you mean, spoiled? Talk about that.*
> *Mike: Well, you got your waiting room out there. You got your TV there. You got your cafeteria upstairs made at your convenience. You got the one with the hot food and you got the cafeteria across the way with the machines and stuff like that. And you can, and then you got machines right there in this waiting room down here. It's uh, come on man, you can't do no better. What more else can these people want? You want to put them in a water bed down there or you know, a trampoline or something? I don't know. It's, it's cool.*

Mike's stories reveal evidence of the multiple informal roles he has assumed in the ED waiting room: monitor and witness, leader, patriarch. Elsewhere in the interview, he emphasizes that he takes pains to sit upright while sleeping in the lobby, dress neatly, keep himself clean, and not clutter the lobby with possessions, calling himself "the vet" of the waiting room crowd. He sets an example for others and is annoyed when they do not observe the unwritten rules of behavior that allow him and others to stay there.

> *Mike: Like me, I come* [to the ED lobby]*like this. (gestures to his neat clothes). But then you have these* _**nuts**_ *that come in there and they messes it up for me. I mean, you see 'em come in; they got bags--and they shove these bags underneath the chairs and they're hangin' clothing off this--they let it be known, you know, what they're doin'.*
> *Int: They're not discreet about it.*
> *Mike: Yeah, at* _all!_ *You know, I'll come and I'll sit. I'm like this (upright posture), I'm watchin' TV, you know. They'll come with these bags and do all this stuff. They go like this here, you know (flops down lying on chair). I mean, Jesus Christ! You know? You're blowin' it for me, here, you know. Because you just lettin' it be known, you know: 'I'm comin' to go to sleep'.*

Like Sam with the policemen in the park, Mike has tried to respect the rules and expectations of the keepers of the lobby culture. His efforts acknowledge to the rulekeepers that, even though he does not want to be kicked out, and understands himself as an insider, the rules are necessary and legitimate. This may be interpreted as a kind of reciprocal respect, in which a bond of collusion is forged. Since it must at times be morally difficult for the security guards to roust people who have come there simply to rest or to get in out of the cold, Mike's attention to the rules of conduct suggests sympathy and consideration for the guards' position and respect for the "goodness" of the institution itself.

Mike's favorite security guard was on duty one night when Mike came into the ED in a "seizure" state. The guard asked him about it later, according to Mike.

> *Mike: He was the one who had to hold me down. He's one of the guys, you know. And he said it kind of upset him because of the fact that he knows me. And to see me go through that it kind of hurt him, too, you know. And*

> *um, then he ask me, he go, 'Well, what causes that, man?' and I said crack! You know, when I said it like that, he goes, 'Crack, so why don't you stop?' I said no! And he goes, you know, 'You tryin' to kill yourself?' I go, no. But he goes, 'Then why don't you leave it alone?' I said, 'Cause I love it, so leave me alone', you know. But it's the truth, you know. Why should I lie about the crack? One thing I'm not going to do is lie about it, you know. They say, well, what causes your seizures, why you doin' it? I can't say. I can say what causes it, which I think is the crack. Why am I doin' it, it's cause I like it. It's, I can't just say,* [snaps fingers] *'Okay, no more crack!' I can't do it.*

The vividness and descriptive detail of this conversation as related by Mike suggest that it was a significant one for him. Being confronted about his drug use in a concerned, worried way by the security guard he has called his "partner" seems to have made an impression, even though he reports tossing off his response in an offhanded, dismissive tone. Ironically, while it was the drug use that gave him "legimate" reasons to be seen in the ED and thus led him to establish relationships such as the one he shares with the guard, he is now confronted with how continued use hurts those others who have come to care about him personally and could even damage this fragile network of relationships. He also reveals another aspect of his moral code: not lying to caregivers at City Hospital.

This concern with truth-telling comes up several times in Mike's interviews. At one point, I ask him if he can tell me about an experience in the ED that was less than satisfactory.

> *Mike: I could tell you but it's not, it wouldn't be fair because it wouldn't be all true. What I mean by that is, uh, me goin' to the emergency room expectin' to get my Dilantins and gettin' what I want, and they say, 'Well, no, I don't think you need them this time because of blah, blah, blah.' I'll get mad. You know. And, you know, I guess kinda because they kind of like got me spoiled (chuckles) in a sense. And I said, 'But I need them. I just had a seizure, and I need my Dilan—' and they tell me no. 'Well, nah, we don't think you need them just to trip around', all blasé, and I'll say, and I'll*

> *go—'Well, I want them.' They go, 'I don't care what you want, you're not gonna get 'em!' And so I may get mad about that but that's not their fault. That's me. They're the docs so they know what's good for me. I just uh, get mad because I didn't get to have it my way, you know.*
> *Int: Hm. You have this sort of expectation that you came in with.*
> *Mike: And, and the fact that I've been through here so many times and the fact that I feel like I'm known by so many people to where, wait a minute, this is Mike here. You're supposed, you're supposed to give me mine, you know. And if I don't get mine, it's like, what're you doin'? ...I just, you know, you gotta give me mine and you, you can change that guy over there but don't change me.*

Truth, for Mike, is tied to notions of fairness and hearing "both sides" of a story, as he reveals above. If he merely told me about being unsatisfied and angry because he was refused his Dilantin, this would only be part of the "truth", and would also imply a certain distance between himself and caregivers, a distance he is anxious to minimize. He clearly sees himself as different from other patients, as someone who has earned special treatment by being a loyal, reliable participant in the institution's activities. He makes an effort to understand the perspective of the doctor or nurse who refuses him, even as he appeals for special treatment on the basis of his long association and familiarity with staff.

Mike is clear that it was the drug use that precipitated his reliance on the ED and the larger institution. While his drug and alcohol use may have begun as a way to cope with losses such as the death of his parents, it has now become the source of further losses.

> *Mike: I had me a little place and I would get my little, uh, rent money and (inaudible). Yeah, this was before I started drinking all that alcohol, and this was really before I started dealing with that crack...Yeah, that shit is what did it. You know, that was also what got me back here goin' and goin', too, you know, uh, and I can't—leave it alone! 'Cause I'm hooked on it. I mean, really. I just—. I know better than anybody that stuff is no good for me. I know that. I can tell you better than anyone can tell you because I*

> *know what it does. I seen what it does. It's made me lose friends, I know it made me lose my wife sometime, and I still go after it.*

Mike's "seizures," as he describes them, appear to be amnesic, rage-filled episodes of violence or near-violence in which he displays superhuman strength and has been known to attack others or hurt himself. He relates several vivid stories of these "seizures" during our second interview. He believes they are related to crack smoking.

> *Mike: You know, like I told my doctors that I'm pretty sure it's the crack, you know, because I never had these darn things until I started doing this crack. Uh, to prove my point is, uh, a lot of times now when they do come is when I'm smokin' it, you know. You know, I, I, you know, uh--and I can feel these things coming on and they're scary. They're so scary, you know, because you know it's about to happen and you know, uh, again, here you go, afraid you're gonna chase somebody or do something crazy to somebody. Because my seizures are not like the seizures that I've seen other people have.*

These seizures (or "fits") have caused Mike to lose friends, he says in the first interview.

> *Mike: You know, I've got friends that don't want to be around me anymore! You know, I got good friends, I go to their house, I ring the doorbell, they go, 'Who is it?' and I go 'It's Mike' and they go, 'Nobody's home!'...You know, that's pretty bad.*

Mike expresses distress over this loss of friends and blames it on the seizures, which he describes in almost Dr. Jeckyll and Mr. Hyde terms:

> *Mike: I have these violent seizures, you know. Real violent ones...People say I go after 'em, you know. And that's--whoa, this is something I would like to see. You know, I would just--. You know, I don't want to have no seizure again. But I would like to have a seizure just to see this here. See myself go through this fit that these folks tell me that I do. Because from what they tell me, it's scary as hell, and God knows I want to see it, you*

> *know. I had people tell me, 'Mike, man, if only you could see what you do. If only you could see how your, your whole face change, man, you, you don't even look like yourself. You know what I mean, you--. But the way you go after people, man, it's--it's not you. Because you like jokes and you like clownin', and you like jokin' with people. And then for you to see this* <u>*other*</u> *guy that wants to grrrr, and come after you. That's* <u>*totally*</u> *not you,' you know. And I* <u>*know*</u> *it's not, because when they're sayin' it to me, I tell 'em, you crazy. You're not talking about me. I don't do nothin' stupid like that. He'll go, 'Bullshit.' ...And you know, some of 'em that they tell me, to me, they sound kind of funny. You know, I'll laugh, and they'll go, Mike, it's not funny. I'll go, it is to me, you know. 'You think it's funny?' Yeah, I wasn't there. That other Mike was there; I wasn't there, pal.*

In one of these episodes, Mike apparently tried to harm his brother. They went somewhere together to buy drugs and

> *all of a sudden I started chasin' my brother around. And my little brother is like twice as big as I am. Okay. He's my baby brother, though. And they said I chased him. I was chasin' him and growling and all this rrr, rah, rrr rah, all around this car and just kept goin' at it, man, just trying to catch him. He wouldn't let him get him, now. And so when I, when I came back around, I was leaning on the paper box, you know, one of those newspaper sales boxes? This part, as far as this part, I kinda remember this part. I remember leaning on the paper box, okay. And I was across the street like this, and I'm breathin' hard, you know. And I look across the street, and I see my brother, and I go, 'Ted!' You know, his name is Teddy Ray. I said, 'Teddy Ray!' He goes, 'Mike?' I go, 'Yeah, man.' You know, he rushes across the street like this and he's crying, right? He go, 'Man, what's wrong with you, man', and he's pushin' me all up against this car, and stuff, so I said, 'Hey, hey, come on partner, what's happenin'?' He's pushin'. I said, 'Ted Ray, stop it, man, what's, what's up?' He said, 'Man, you tried to kill me, man, you got--' I mean, he was crying! He was really upset. So this lady in the liquor store named Janie, she called me. She said, 'Mike, come here!' You know. So I go in the store and she goes, 'I don't know what would have happened if you would have caught your brother, man. But*

> *you--why don't you leave that shit alone?' You know, talkin' about the crack, right? She said, 'Man, you went crazy. You throwin' shit around and you're trying to kill your brother. You doin' this.' And I'm goin', 'When did I do this here?' 'A little while ago.' I don't remember none of it! All these folks sittin' on the street saw me do this. And I remember absolutely nothing, you know.*

Here the community around Mike is both bearing witness and testifying for him; people whom he loves and trusts are telling him that it's not some other guy doing these things: it's Mike. This story contrasts with the previous one in which he was told, "It's not you" and he blames the behavior on "that other Mike." Like the story about the security guard, this is a story of being confronted about his drug use by someone who matters to him, someone who knows him and is concerned for him, others puzzled that this behavior does not fit with their understanding of him. It is also a story of how these "seizure" episodes and his drug use have the potential to harm not only himself, but those he loves and cares about, another reason he feels safer in the ED lobby than, perhaps, in a relative's home.

Mike's "seizures," whatever they represent from a physiological standpoint, are very meaningful to him on another level. In one of the longest of Mike's narratives, he tells me about a couple from a suburban area who saw him on a TV program about homelessness and subsequently invited him to come and stay with them in their home. Mike lived in a cottage behind their house for several months, during which time he says he came to know and love this man and woman, who apparently decided to do this out of charitable intent alone. This still amazes Mike. I asked Mike about whether he had any of his "seizures" while staying with this couple.

> *Int: Did you have any of these seizures when you were there?*
> *Mike: No.*
> *Int: Because you weren't doing crack, or why, do you think?*
> *Mike: Uh, (pause) I wasn't, I wasn't, uh, I was takin' my pills like I was supposed to. um--*

> *Int: Your anti-seizure pills.*
> *Mike: Yeah. Plus, I think, because I was happy. I think a lot of times bringin' on seizures and stuff like that is stress and stuff like that. But I was happy while I was there, you know. I--I guess I didn't have time for no doggone--I wouldn't let it in. You know? Uh, you know, everything, I enjoyed those folks. I got to show them how to play certain games like dominoes. I showed 'em how to play dominoes and they loved the game, man, they used to wear my ass out, man. 'We gonna play dominoes tonight, Mike?' I said, 'Oh, God! Maybe.' Then they'd come back there, knockin' on the door, say, you want to play some dominoes with us? I go, shit! What'd I do that for? But now I got 'em stuck on playing dominoes and then I showed 'em how to play Bid Whiz. You know, these card games. Oh, man, we used to enjoy just havin' fun playin' those games.*

Mike's understanding of his seizures includes his level of stress and his level of happiness as etiological factors, in addition to the crack. Mike does not experience his mind, body, and spirit as separate and distinct from one another; being "happy" can be preventative of bodily dysfunction, as can "not letting it in." While the clinicians caring for Mike were baffled at his repeated visits to the ED and his failure to keep his follow-up appointments, it becomes easier to understand this failure once we see it in a larger context. Mike is happily engaged in the world of City Hospital, a place where he cannot do drugs, at least in a regular or overt way; where he will be protected from harm and from harming others should one of his "seizures" occur; and where he is informally acknowledged as one of a group engaged in good work. In Mike's understanding, his seizures can be prevented or minimized by taking Dilantin and being happy; it is not really important to him to see a neurologist and find out more.

Mike was stunned by this couple's generosity and still recalls it almost wonderingly:

> *Mike: These people were so friendly, man, they gave--wanted to give me everything I want--anything I wanted, they'd give it to me. You know. And*

> *then they trusted me to the fullest; that's what I loved. They trusted me so much, man, until that just turned me on. These was just some workin' people. I hadn't been at their house for what? Four or five days. And they split and went to work like it was the thing to do. 'Well, we'll see you.' First he leaves. 'I have to go to work. I'll see you when I get off work.' You know, I'm thinkin', well, somebody's got to uh, be at home. And then it's like, wait a minute, he's leaving me here with his wife. He don't know me. But he, he goes anyway. Then, you know, she uh, 'Well, I got to go, go to work. Uh, if you need anything, the food's here,' and this and that and all this. I go, 'All right.' You know, I'm puzzled. It's like, okay, what part of the game is this here? You know, it's a test on what? You know, that's what I'm thinkin'. You know, it's a white couple, and I'm thinkin', hey, I'm black, you don't know me from Adam, you know, and it's like--'Okay, I'll just--play along with the program, here.'...So uh, this went on and I said, 'Well, they just trusted me.' I guess they was hopin' I wouldn't steal nothin', which I didn't. ...And they was so nice to me, man, there was nothing I could give these people back. You know, I, I did a lot of garden work around their house for 'em just for the hell of it. You know, they didn't ask me to do any of this stuff...I just got, kinda paid my way like that, you know...a few little things. I painted the garage for 'em. I did a whole bunch of good stuff, you know, and they, they were shocked and really pleased with what I did.*

This is another story of recognition practices, in that this couple somehow saw something good in Mike and picked him out as worthy. The usual way Mike experiences the world is so bounded by others' racial and class stereotypes that he could initially only interpret the couple's trustingness as a game or test. Perhaps it was. But once convinced that their trust was authentic, he was able to extend himself in the relationship and also found ways to "pay his way."

Despite being "happy," Mike says he decided after about six months to move on and out, thanking the couple for all they had done. While he is genuinely grateful for the couple's generosity, the situation's lack of established expectations and boundaries and the minimal cultural precedent for such behavior on the part of the couple seem to have made

Mike uncomfortable, for he says they were just "too nice." In this situation, the boundaries for expected conduct were indistinct and enforcement practices ambiguously defined or absent. Since Mike lives with constant anxiety over the possible appearance of his own "Mr. Hyde," these circumstances may have been too risky for him to tolerate, particularly if he was tempted back into crack use.

Now he worries that the couple who helped him might seek to aid some other person who might, unlike himself, do them harm. He uses this story to show again that he is an honest person and that he does not harm others or take advantage of their generosity.

> *Mike: I just hope that they--like they picked me. I just hope they don't pick the wrong person. That's what I've been worried about.*
> *Int: That they might find somebody that--*
> *Mike: Yeah. You know, because--*
> *Int: --they want to help out or something.*
> *Mike: --And that would hurt me. That would make me want to kill somebody if they did that to them folks 'cause they was so nice. You know. And it's very easy to find the wrong one.*

By the second interview, there is a marked shift in the way Mike talks about his friends. Mike no longer blames his loss of friends on the "seizures."

> *Mike: I don't have any friends. It's associates, you know. Everybody I used to call friends they've all done me some kind of way, so--I don't want no friends. (pause) Can't trust nobody. Every time I put my trust in somebody, somethin' bad happens.*
> *Int: Like what?*
> *Mike: They steal from me. They lie to me, you know? I don't know. I just don't want no friends...I don't know why they do it. I never done anything wrong to them to take stuff from me and lie to me, you know?*

> *Int: Well, the last time I talked to you you had said you felt you'd alienated some of your friends because of what you were doing with this neurological thing--*
> *Mike: Well, a lot of 'em cut me loose behind that, you know. But they, a lot of them didn't so much cut me loose behind the crack, or behind me smokin' crack. It's, it's behind the fact that I wouldn't come around them and smoke it. ...As long as they thought they could get somethin' out of me, it was all good. Was the only way it was, is all. And it took me a long time to realize that, you know. I thought they were friends but then I would check a few people and I would, 'man, you know? The only time you laughin' and talkin' and jokin' with me is when I'm giving you something. You don't think I'm gonna give you nothin', man, I ain't welcome in your house. You say, 'well, I'm fixin' to go to bed now, uh, you know, you gotta go.' But if he thought I had any kind of money or somethin' in my pocket, I can stay as long as they think I've got somethin', you know. And are these friends? (softly) They're not friends. They're just assholes.*

Whereas in the first interview Mike mourned the disrupted relationships with his friends, he now bitterly castigates those friends as false and opportunistic. This seems to indicate a shift in Mike's self-understanding and suggests the possibility that he may be struggling to resolve the contradictions inherent in having "friends" who abet self-destructive behavior. This interpretation is provided with some confirmation as we continue to talk:

> *Int: It must be kind of lonesome.*
> *Mike: It's very lonesome. But I'm trying to get used to it.*
> *Int: Especially for a guy that seems as friendly as you do. I mean, you seem like the kind of guy that likes to have friends, that likes to talk.*
> *Mike: I love, I love people, you know. I mean, God, I'll go around, and I'll --I don't like bein' alone! Okay. I'm lonely, a very lonely person that can't <u>stand</u> to be alone. And it has been like that lately. But I got this money that I've got comin' this time. I want to get me a nice shave, you know, clean up. I like lookin' good if I can...And I want, I want to look good and then go out, man, and just--talk to some pretty girls or somethin', you know? You*

> *know, like there's a lot of movies I want to catch up with....I would like to get me a studio apartment. But that's, that's gonna take some time. So what I'll do is, is I'll get me a room somewhere. But I don't want a room down in [skid row district] because--that's, that would be just like committin' suicide, you know?*
> *Int: How so? I mean, I know it's not a great area, but--*
> *Mike: You know--with me, still, you know, uh, I'm not drug-free, I'm not alcohol-free, and down in [skid row] I don't really--you don't always have to have any money to do either.*
> *Int: Uh-huh. It's just there all the time.*
> *Mike: Yeah, it's* <u>constantly</u> *there. You can go into a group, you know, people that's drinkin' and stuff and you start talkin' with them. 'Hey man, you want the bottle, man?' 'Cause a lot of winos are very friendly, you know, especially when they're getting drunk. And they go, 'Ah, come on man, drink with me; here!' You know, and they're passin' the bottle and you could sit there and not have a penny and get drunk. You're drunker than them. And they're payin' for it. You know, and same with the drugs. You know, there're some drug people that be doin' certain things and, and they'll be, after they get their little high on 'em, and they get happy, and they'll go, 'Hey, anybody want some of this?' You know, and then you'd be doin' it. It's just too easy to come by down there. That's, that's, that's where the stuff* <u>lives</u> *at. And, uh, most of these places where I know where it lives at, I don't want to go there 'cause I'll die there. You know, I already know that. So I'd rather be on this end...That's what I be doin'. I be walkin' around shopping, see where I want to go. And I've got a few places lined up. That's if I can get in 'em.*

Here the crack is characterized as having a life of its own: if it lives, he dies. Mike is having a conversation with himself about how to get reconnected with life in a way that is not self-destructive. If he is social, at least with his former "friends," he may slide back into a pattern that frightens him, in which his very sense of who he is may be shaken at any moment by a "seizure." In this context, the relationships Mike has developed around the ED lobby take on a new implication; as life-affirming, literally lifesaving associations, they offer alternative possibilities and they reflect back a view of himself as worthy, as honorable, which he strives to live up to.

Trying to live up to these expectations involves real conflicts for Mike. For example, his little brother, with whom he is close, still uses crack.

> *Mike: Every once in a while he'll come look for me, and go, 'Hey, what'cha doin', dude? Let's go party!' You know. I go, 'Naaw, nah, that's okay.' You know, I bust his bubble a couple times lately because I haven't went and partied, you know, so, somethin' he can't take. If there's anybody he can party with, he know he can with me. And when I, when I tell him no, it's like, 'Huh? You tellin' me no, of all people?' You know. 'Yeah, believe it or not, I don't want any.' And he can't believe that, you know. I have to put a stop to it sometime. I mean, I don't know if you noticed my new [Medicaid] card, the new white cards? I like that thing. You know, I got all my cards and, you know, I'm tired of these blue sheets, you know?*

Immediately after this story of change, Mike continues into a discussion of how the staff in the ED recognize him on sight, how he is known all over the hospital; this smooth transition from turning away from crack to being known in City Hospital lends support to the notion that Mike's relationships with City Hospital and its people are crucial to his emerging identity as a legitimate, respected person. The "white card" is new and represents something respectable that he can carry in his pocket; the "blue sheets" are a record of the past, of his "fits," and of that part of himself that is prone to unpredictable violence, a part he does not want to accept and which he fears being unable to control. He is now able to imagine a future in which he will not have to pretend, perhaps, in order to "pass."

> *Int: So you're gonna get an apartment or something?*
> *Mike: Yeah, I'm gonna get a room. I got to get somethin' 'cause I'm tired, you know, I really am tired.*

> *Int: And then what do you see yourself doing? I mean, where do you see yourself in one month or three months or--*
> *Mike: Bein' happy. Bein' with my boys. Um, goin' to movies, doin' things I like to do, things that I've missed, that I haven't done in a long time. You know, goin' to the zoo, goin' to the beach, you know; stuff like that. I want to live again. Instead of just walkin' around panhandling. Bein' like now, I* stink. *And uh, that kind of stuff, I want to get behind me again.*
> *Int: Have a more normal life, it sounds like. And what, what about the drinkin' and the crack?*
> *Mike: That is, sure enough I'm tryin' to put behind me, 'cause I'm doin' pretty good as is, you know, uh, hopefully I won't get back into it. But then I can't say I won't, you know.*

This qualification is very similar to one Jack made in my first interview with him when I asked him about his sobriety:

> *Jack: I, you know, this isn't, oh, a thing of honor and strength, this is a thing of luck. And it's day to day. And I just try to get enough rest, and try to eat, and try to keep a little busy; I don't like work, I'm as lazy as ever, but I know if I don't, I'll be in worse shape.*

They are both scrupulously careful not to assume too much certainty around their substance use. Theirs are not classic stories of redemption through faith, nor are they stories of pulling oneself up by one's own bootstraps. If there is redemption, it is temporary and uninvited, much more a matter of grace and tiny, incremental, almost invisible testing out of new ground ("trying to eat," for example) than of control or belief, rational or mystical. Trust in their own agency, for Mike and Jack as well as for others in this study, is viewed as warily as trust in others; both have often been sources of disappointment and failure. Recovery from drugs and alcohol, therefore, is not a matter of "just saying no," but a fragile, even ephemeral possibility.

Yet it *is* a possibility. Mike is trying to build a bridge between two worlds, but its construction depends upon connecting with others as much as it depends upon controlling himself. Earlier Mike admitted that:

> *Mike: I've been clean simply because I haven't had any money. That's not the only reason, though. But I have been clean, you know, for a few days or so and I'm doin' pretty good. I'm proud of myself, you know? I didn't think I'd go this long. I was--in fact, I wasn't really tryin' to but it happened.*

Being clean is a matter of luck, a gift; it is not viewed as a wholly volitional, intentional decision made by the individual. Haunted by the "other Mike," he is acutely aware of the limits of personal control. There is a limited volitional component, as in "not letting it in," but Mike does not experience himself as autonomously controlling his life and circumstances.

While Mike is reluctant to characterize himself as even trying to quit drugs and alcohol, his narratives center around establishing an identity in which they are no longer primary. At one point, he even hints at future possibilities he will only permit himself to discuss in an as-if way:

> *Mike: And like around here, a lot of the security people, well, a lot of the staff, they know me. If I, if I was uh,* [to] *come and apply for a job here as a janitor or somethin', I'll probably get it. (chuckles) You know? Because of the fact that quite a few people around here know me.*

For Mike, City Hospital is a drug-free safe haven, a place he can rest and socialize with others without the risks of the streets. But it has become much more. It is also the center of a community in which he rightfully claims a place. In a very real way, City Hospital is a lifeline for Mike as he tries to find a place to stand. City Hospital is public goodness made visible, a remnant of an earlier time when caring for the less fortunate was a more explicit part of public discourse. But what is also important about Mike's story is that he is not just a care recipient: he gives back to this community of care through his humor, his small gifts to others, his helpfulness, his respect for and modeling of proper behavior, his sharing of food, and his loyalty. This goes largely unrecognized and unacknowledged by the formal caregiving network, where providers view him as vexing and baffling for his "noncompliance," and, further, feel that they are doing nothing for him. Once Mike's story is understood, however, it becomes possible to see that providers are actually doing a great deal for Mike by continuing to see him, by recognizing him, and by caring about him. This kind of care, however, is not captured by economic models, within which Mike can only show up as a liability.

Economic and power discourses predicated on a view of persons as wholly autonomous agents and rationally calculating utility maximizers (Wolfe, 1989) do not permit Mike to show up as someone struggling toward a different way of life, someone trying to extend his capacity for moral action. When efficiency is the driving value, someone like Mike can only be seen as an obstruction to smooth functioning, as we have seen in so many other cases throughout this study. When power issues predominate, Mike is viewed as a "scam" artist, a slick, conniving manipulator of the system who is trying to exert power through resistance to medical control. Either way, Mike can only appear as a problem, not as a fully human being whose actions have a moral logic. When personhood is narrowed in this way, it becomes harder and harder to see--and sustain--*community* where it does exist.

Hospital Community as Sustaining Community

Jack, the former "frequent flyer" who is now a volunteer, has likewise established himself as a contributing member of the hospital community, albeit in a more formalized role. But he is by no means exceptional in this regard. People with mental illnesses, chronic diseases, and even homeless people, I learned, are regular volunteers, contributing sometimes astonishing and hitherto unrecognized talents. A social services worker recalled learning about homelessness--and about herself--from a man who volunteered making gift bags for patients:

> *Social Services Worker: Um, so he came through the emergency department, was homeless, or always on the edge of homelessness. Um, uh, was HIV positive. Um, was just, was dealing with substance abuse issues. And was... one of the most engaging, bright, creative, uh, (inaudible) souls. You know ... It's, uh, these people just put me--I just become very, uh, kind of awed by their incredible strength. Um, that they still manage to bring, without bitterness, to the world, when I would be just furious and probably in jail in no time. You know?...*
>
> *Uh, so, I, I, I just--I, I think all of these encounters have just been remarkably, uh, I don't even know what the words are--humbling and, uh, inspiring, and tragic, and powerful...*
>
> *He'd been staying in shelters and that, that, that became a problem throughout because, um, he, I mean, he,--some of the shelters were very dangerous and some of the same people, I'm sure, who attacked him were staying in the shelter. And, um, he was trying to stay --and I think doing pretty well for a while. Staying away from crack and, um, was just all over the place. It felt very unsafe. He's also a very meticulous person, um, and really liked dressing well and can--and sewed. I mean, just was an incredible--just hand sew so gorgeous, like designer type clothes, I mean, overnight. He was just amazing. Um, just absolutely talented. And, uh, his things would get stolen at the shelter. It was dirty. So he found, I think, a little band of people, he trusted and they basically stuck together and, um, slept down by the water or somewhere. Found a place to hide. You know, he'd find a place to hide his stuff during the day, and then come to the hospital.*
>
> *Int: And volunteer.*
>
> *Social Services Worker: And volunteer. Um, the volunteering, I mean, he had a wonderful heart. Um, you know, very giving person. ...*
>
> *Anyway, so it was a place to come every day just to feel like he was contributing, and he was! He was extremely sociable. So everybody knew him. Um, and he knew everyone. And he felt engaged.*

This story points again to the "nonmedical" and noneconomic roles traditionally provided by hospitals, which as institutions of public care have symbolic and practical relevance for communities. Here the hospital community has a place for a person who is otherwise ostracized from society by his HIV status, his drug problems, and his poverty: a place within which he can contribute to the well-being of others. When we regard "dependency" as pathological, we close down the possibility that such "dependent" persons are capable of making contributions that enrich the common good. Further, we deprive ourselves of the extension of our moral horizons that working alongside such persons, understanding their stories, can promote, as the teller of this story reminds us.

> *Nurse: But you see this incredible transformation happen to the people [who become volunteers] because they become useful and a way is found for them to do something that's, um, valid, valued. And here they're part of the community.*

Sometimes being recognized as part of the community means an easing of burdens borne in relative isolation. A social worker told me about one "frequent flyer" she remembered well, a Chinese woman:

> *Social worker: Everybody would know Sandra. Um, here they had her down as a manic depressive and everybody was convinced she was a manic depressive. I don't think she was. Um, Doctor Hardy referred, referred her to me initially because, uh, she had wound up over in the [clinic area of the ED] and her father had recently died, and he saw it a case of--and she lived with her mother and her mother's an alcoholic, and he saw that she was coming more and more--and he thought it was because they hadn't dealt with grief counseling. So that's how I first met her. And then M[nurse] brought her to me, I think, once or twice. She'd come in for seizures all the time, and people saw her as not quite legitimately here...I never thought she was illegitimately here, actually. She was a bit of a hypochondriac. Um, but seizures are seizures and, I mean, she definitely had many, many witnessed seizures and they didn't know how to stop them. Uh, and, uh, she had many, many doctors' appointments that she would keep very, very detailed little calendar notes of all of her, um, you know, very well-organized,*

very beautifully printed. Uh, and she had pressured speech; she never stopped talking...

Um, I used to see her a lot, like two or three times a week, I guess, she'd come by, and if I wasn't busy--and I was interested in her in the beginning, just sort of what was all this about. And I got her to go to an acupuncturist because I thought it would help her hypochondria to have all those needles put in and have that kind of attention. (laughs) It worked for awhile; she--'Oh, they put in 14 needles,' you know, like this is really treatment. (uh huh) And I also thought maybe they could stop her from talking so much. Who knows what kind of balance they could put into her system?... and they spoke Chinese and she was bilingual and, you know.

And then, in terms of her mother, what was happening--oh, it turned out to be so interesting. She was getting into more and more fights with her mother and then she would get really distressed and really upset. And, of course, she must have been a very maddening--um, she was in her 40s, I think-- because she never stopped talking. Um, but also, after the father died, the mother was drinking very heavily and also smoking all the time. And Sandra was very scared that her mother was going to die. So she would take away the alcohol or try to take away the cigarettes or tell her mother what to do.

And at one point the family was putting her out or--I can't remember. There was some crisis. And I wound up talking to the brother, who was a high-functioning regular person with wife and kids and, uh, and they were seeing her as totally hateful and disrespectful to the elder because she was telling her mother what to do and, uh, not being respectful. And I explained that it was really 'cause she was scared that her mother was going to die, and that this was her way of showing that she cared, which the brother actually understood when I said that. But there had come to be like this total impasse of what was going on.

So the most wonderful solution on this one turned out to be talking to [volunteer coordinator], who's the person who runs the volunteers, and trying to figure out was there anything useful she could do, 'cause she felt so useless. And so actually she's now totally critical to the functioning of the [hospital medical] library...And, uh, works there like three or four days a week, and all of her--she can't talk in the library so she doesn't drive the coworkers crazy. ...And, and it's useful and she knows it and, uh, I don't think she comes back here much. I think

> *some of her seizures were really stress related--among other things, and, uh, uh, now she's like a useful member of society.*

The death of her father left Sandra alone at home with and feeling responsible for her grieving and alcoholic mother, whose welfare became a preoccupying concern and a source of family conflict. In this context, as with Mike, Sandra's visits to the ED may be seen to be an expression of social and psychic distress as much as medical helpseeking for seizures, but in the context of medicalization, such social distress is de-legitimized as a public concern and her problems are initially viewed as "diagnoses": seizures and manic-depressive illness.

Although the social worker questions the psychiatric diagnosis, it is clear that Sandra exhibited symptoms that would interfere with her ability to function independently in a less forgiving setting. The social worker's perceptive understanding that Sandra's distress was not reducible to her medical diagnoses led to a link with a larger community within which Sandra could assume a valued role. This story points out how necessary it is that medical care providers be able to recognize and acknowledge more than the narrowly-defined "medical" problems for which they consider themselves responsible, but it also reveals how the functioning of an "efficient" and effective "medical" system is predicated on practices of care. Caring practices take time and require resources beyond the technologically-oriented "quick fix" approach of biomedicine. Sandra's story shows that communities of care can effectively relieve pressure on medical resources and help sustain families as well as individuals.

Threats to Communities of Care

Yet, as I heard again and again from providers and patients, caring communities within the hospital setting are in jeopardy. As referral resources have dwindled due to budget cuts and increasing demands for public services, health care providers throughout the hospital have been exhorted to focus their attentions on efficiency and cost controls.

The restructuring of the private nonprofit sector (Estes & Alford, 1990; Estes & Binney, 1993) has meant a diminution of the differences between for-profit and not-for-profit hospitals, and with the rise of Medicaid managed care enrollments and dwindling public dollars in a political atmosphere hostile to public programs, public hospitals are likewise pressured to focus on economic competitiveness in order to survive. The market orientation that has overtaken health care dominates the ethical discourse of providers; over and over, when providers described a morally troubling problem, they ended with a kind of reluctant resignation to the supremacy of the economic "bottom line." As the common moral language within which care could be conceived disappears, the hospital is increasingly isolated from the larger community it is intended to serve and less hospitable toward the growing population of those who have need of (unprofitable) "almshouse" services.

For providers and patients, this has meant a change in the way "frequent flyers" are cared for and perceived.

> *Nurse: [talking about her early days as an ED nurse, 15-20 years ago] We had more of a home-like atmosphere for the chronics back then. There weren't as many, you weren't as busy, uh, you know, you could put Charles to bed or Fred Nickels to bed, um, you know, for an eight hour shift. And, and that wouldn't be a problem. You just can't do that now. You don't have the time. You don't have the room. Um, and you could put up with more of their antics. Lie them down for a little bit.*

This nurse calls attention to the deterioration of the traditional almshouse functions of the ED. In the former 'home-like' atmosphere, patients could show up as human beings, not just as their disease or injury, and those who came frequently were not experienced as burdens. Now they are regarded as a problem, because the pressures of more ED patients, more "frequent flyers," and less "time" mean that those who have less and need more are less welcomed.

> *Nurse: [We would] socialize with them a little bit more. It was a more, it was a more friendly thing. I don't know; people aren't quite--I don't think that most of the ER abusers--and I don't think you see that same--, if they are an ER abuser, they're kind of in, treated, and out. They're not people who hang around and socialize with you like they used to. Part of--twenty years ago--part of coming in for your regular ER abuse, was then to sit around and socialize with the nurses and doctors. And you had not just this ER abuse relationship with them, but you had kind of a friendly personal relationship with them, too. And I, you know, I can't think of anybody in the last ten years new-patient wise that you have that kind of relationship with. ...I think that we have new people that abuse the emergency room; I'm not sure that you end up with the same--semi-caring, ongoing relationship where you know their husband and you know their children, and you know where they live, and--you just don't have time to do that anymore.*

This nurse, like the nurse in the last chapter who says she still feels idealistic "underneath," strains to find words to talk about the engaged, caring relationships she recalls positively from her early years as a nurse; she, too, seems to feel vaguely self-conscious about expressing these concerns. Benner (1994c) has pointed out that caring practices have traditionally been linked to the private sphere and thus lacked public language; this nurse's language suggests both a distinction between the public and the private (as in 'they're *kind of* like your family,' heard earlier), and a link between the kind of nurturance families carry out and that which nurses do.

For example, she qualifies her use of the word "caring" by calling those remembered kinds of relationships "*semi*-caring." Her efforts to describe this suggest a longing for a kind of nursing practice that incorporates this ethic of connectedness. She calls our attention to the difference between caring for patients, with all the contextual and moral richness such relationships involve, and the present task-focused processing of bodies. Participation in public caring practices like nursing, as Benner (1994c) notes, "is an expression of a common good" (p. 143). Twenty years ago, heavy users of emergency services were not understood first and foremost as a problem; rather, they were people with whom providers had "friendly" relationships: they were part of the ED community, not merely "abusers."

> *Nurse: I don't think the frequent flyers have changed. I think the practice has changed...we don't have the time anymore.*
> *Int: And is that because there are more patients or is that because there's more work demanded of you with the ones that you--*
> *Nurse: It's both, it's both. The census is much higher...And the acuity level has just gotten--skyrocketed, especially on the night shift. I mean, we admit 30, 35 percent of our patients at night, and their acuity levels are usually very high. Uh, or their acuity levels are high because they're hard to deal with. Uh, but we don't have the luxury of spending the time talking to these people and getting to the bottom of it, or taking care of their creature comforts or hiding them.*
>
> ****
>
> *Nurse: We were talking about how much worse it's gotten--not only do we get more frequent flyers, but somehow, we're getting sicker and sicker and sicker and sicker people.*
>
> ****
>
> *Nurse #1: That might be a function too that there's so many more people.*
> *Nurse #2: I mean, society is changing but--*
> *Nurse #1: And when you have more volume, more volume of the same kind of character, that really consumes a lot of your nursing time. Then you can give only so little time to begin with. And, and, it's just barely, you know, like--I mean, we don't even like start IVs on some people that we know are just here for alcohol intoxication. And we don't do the IV, the, you know, thiamine in the, if, um, you know, multi-vitamins and then, when they wake up, sit them in a chair and let them sit and jell out and get their land legs for a while, and get them a bag lunch and all that stuff. So our care is different in a way that way, too.*

These concerns were echoed many times over by nurses at both the study hospitals. This intense discourse of scarcity and time-pressure begs deeper questions, such as why there are now more and sicker patients using the ED for care, why the patients are harder to deal with, and why, if they are seeing more patients, there are not more nurses and doctors to do the work of caring for them. These perceptions by clinicians are not mere conjecture; the phenomenon of "sicker and quicker" discharges has been well-documented (Phillips & Cloonan, 1987; Rogers, et al., 1990; Wood & Estes, 1990).

The ED setting, with its ebb and flow of patients, encourages a kind of crisis mentality that sometimes makes it difficult for providers to articulate and formulate such questions, but nurses clearly felt that something was not as it should be. Their stories pointed to both external and internal changes that directly affected their practice and the lives of "frequent flyer" patients.

Deterioration of Other Public Services.

The hospital was once a small portion of a much more extensive public services system in most communities. Estes and Binney (1993) point out the massive losses of government support experienced by social services, community health, and community mental health in the last decade. In this study, nurses spoke of the decline of public schools, the limitations of public health programs, and the dwindling numbers of public hospitals. The deinstitutionalization of the mentally ill, as noted in previous chapters, was a major source of concern because local programs seemed inadequate to meet the needs of former state hospital patients:

> *Nurse #1: [State mental hospital] closed down, and they shut [local mental health unit]. Yeah, they're all out in the community, and we're seeing--we used to see them--rarely, right? Now they're frequently in every week, and take a lot of time.*
> *Nurse #2: I think we see more overdoses, too. This last couple of weeks we've had at least, you know, one or two a day...(inaudible) before that, uh, that's the only way they seem to know to [ask]--for help--*
> *Int: Oh, you mean you think they intentionally overdose.*
> *Nurse #1: Oh, yeah. They're all intentional. They're not heroin.*
> *Nurse #2: Fighting with their boyfriends and the boyfriend wants to leave and trying to keep them--*
> *Nurse #1: They live on a tightrope, there, of uh, coping and not coping.*

Community support can mean the difference between coping and not coping for both patients and providers. When ED caregivers know that the homeless must enter a lottery for the chance at a shelter bed on a stormy night, they assume a burdensome moral liability as they turn a patient away for lack of medical "legitimacy." When they refer patients to clinics at which it takes months to get an appointment, or to providers whom they know are reluctant to accept Medicaid patients, they are left holding one end of the "tightrope" as the other end collapses.

> *Nurse #1: No, I was just thinking, uh, a lot of these clinics, I mean, we all know, the outside, uh, support, they're not there. The clinics are open 8 to 4--these people sometimes don't get up until 4 in the afternoon. And I always think sometimes even home follow-up visits, for, particularly for these people involved with home nursing, uh, support. That would keep them out [of the ED]. I mean, they--they say it costs money but every time they come in here, just think of the money involved, you know--and some of these people do have real, I mean, they do have medical problems. And, uh, more support systems, but you just can't--I mean, you can't get clinics to be open. There are waiting lists, um, and some of the way they're triaged in clinics--*
> *Int: Is that true that they have waiting lists? I mean, it's like--*
> *Nurse #2: Yeah.*
> *Nurse #1: You know, or you can't get an appointment for three weeks.*
> *Nurse #2: Same day appointments have to be called in at 8:30 in the morning--*
> *Nurse #1: And these people don't even get in bed until, you know. And so the system, so that's why they keep comin' up here 'cause no one's going to refuse them care here.*
> *Int: Mhm.*
> *Nurse #1: And especially these people with all these chronic problems. And so it's a vicious cycle. And it's true of the young females with abdominal pains. I mean, you're not going to get caught with an ectopic [fallopian tubal pregnancy] triaging them out of here. You could triage them somewhere in the clinic, you know, maybe for initial work up, if they look good, you know. That's just kind of hard to do. There's no support system... See in the morning, but in day time, they'll do that. Evening hours they won't 'cause there's no clinics open. A lot of times, they know that and their lifestyles, they don't wake up until the evening, so --but I think sometimes having nursing care support go to them would be--maybe it would, it would help. You know, I think. Not that it would--or just some support systems going to their house maybe could help...That's why I think you rarely--I mean, I don't know the answer--but you rarely see them--no, you don't see them turn around. Because no one-- of course I'm not on the other end, I*

> *don't know who--where they get hooked up. I think they get just, you know, fed back out in the system and the system is just a vicious cycle. I'm not sure how much time is invested to, you know, sit down and try to work with these people and say, hey, this is not cool. You know, this has gotten-- Maybe they do.*
>
> *Int: Mhm.*
>
> *Nurse #1: I don't see the other side of it. I only see the ER side, you know, and that's a lot of time invested and (inaudible). Getting to the root of the--or put phone calls, how are you doing today? You know, I don't know. I remember as an office nurse, um, having one lady like this in the office, when I was an office nurse, and she was--she had bad COPD and everything but she would call in every time I was there, three days a week, she'd call in, you know, with complaints. But I just tried to direct it to the physician and we tried, you know, we tried to work with it that way and you just kind of expected her. And, yeah, she was going to go to the ER at times, but I think a lot of times having that--someone to talk with, you know, not that it was--I didn't like talking to her all the time, you know, it was bothersome, but somehow these people, I don't know...*
>
> *Somewhere there's a missing link and I don't know how to reach these people. And the system, you know, that's where I think sometimes visiting nurses, if you plug them in to say, I'll be seeing you Monday, Wednesday, Friday, and maybe taper off, you know, but to a certain point? That would save a lot of money versus these visits in here. But I don't--who's going to hook them into this system? You know, where is the piece that's going to hook them in?*

The "missing link" here is a larger community of care that supports caregivers as well as patients. While both the ED sites of this study had social workers whose practice focused on the ED, their options for referrals were often painfully limited, and the emphasis on efficient care means little time can be spent with any one patient, creating ethical conflicts. Davis (1991) has called attention to the way the press for efficiency can even mask the ethical uncertainty that prompts providers to reflect on their practice. As this nurse notes, drawing on the moral source of her own past clinical experiences, engagement with patients may be "bothersome," and certainly it is inefficient when efficiency is measured in terms of rapid processing of patients, but it offers the possibility of contributing toward a different kind of common life, a life where people can "reach" one another.

Access Revisited.

As the commodification of care accelerates, patients who are not wealthy enough to be "good customers" find themselves left with fewer options. The economic squeeze in health care has meant decreasing access, as has been documented in the literature (Komaromy, Lurie, & Bindman, 1995; also see Chapter One). Providers and patients both addressed this issue.

> *ED Nurse: And so you have a lot of--I mean, we see a lot of return PIDs [pelvic inflammatory disease], and a lot of uh, or no-pay people. No one wants 'em. I mean, they come back here because no one--and I can't blame the private physicians, because they need so much, you know, revenue, but--so--so they come here.*

Besides private physicians' well-documented reluctance to take Medicaid patients (Komaromy, Lurie, & Bindman, 1995; Kotelchuck, 1989), there are problems with long waits for appointments in the public and nonprofit clinics that do accept such patients; many ED nurses alluded to their experiences with patients who returned to the ED with problems because follow-up appointments could not be scheduled until several weeks later. Such circumstances certainly contribute to increased use of ED services by the poor, but as noted in Chapter One, even increased access may not necessarily result in decreased ED use. Jack gives us a first-hand glimpse of a Medicaid patient's experience with a private doctor's office:

> *Jack: They give you Medicaid. But I went to the doctor's office, I called, 'I'd like to make an appointment to see Dr. B.' 'Okay, sir, what's your name?' I tell him Jack M. 'I live at--well, right now I'm stay--' I give him a friend's address because I'm living on the street or in a shelter. 'Okay, and what kind of insurance do you have?' 'Oh, I have Medicaid.' And you hear, 'Oh, I'm sorry, the doctor*

> *doesn't take Medicaid.' Click. Now the doctors that do take care of Medicaid, or don't--or maybe they don't even want that. Can you believe that? They won't take it. They won't. It's too much bureaucracy! And plus they don't give 'em enough money.*
>
> *Plus the patients they get all stink. They all look like they came out of some kind of cartoon book. And there's no money in it. And you never see any satisfaction. You could treat this guy with aspirin, pain pills, and vitamins for 200 years. He's still going to come in with dirty clothes and needing a shave. And a bad attitude and the same problem because he's sleepin' on a cardboard box underneath some bushes with a please don't rain sleeping bag, without a shower. He comes in and all the other people that have paid $50 for the doctor are hiding out in the hall so they can breathe. This guy reeks from Ripple wine, tobacco and BO. You're doomed.*

As Jack's description suggests, and recent research confirms (Komaromy, Lurie, & Bindman, 1995), there are plenty of noneconomic reasons why a physician might refuse to see Medicaid patients. But Jack also offers a glimpse into why a poor person living on the street might not choose to go to a private doctor for care, even if one can be found who will accept Medicaid. Sitting in an office waiting room with a group of well-dressed patients, for some, may be too painful a reminder of how much one has lost, or how much one will never have. For people on the street, the ED is a much more comfortable and comforting place, a place where you "come as you are." It is, as Mike's story showed, a tiny community.

Managed Care.

During the period of this study, the two states in which the research was conducted were enrolling large numbers of Medicaid patients in managed care plans, many set up on a capitated model under which providers would be paid a specific sum of money for the care of each patient or for the care of a group of patients, rather than the traditional fee-for-service model. At City Hospital, this was cause for intense concern that the "private" managed care plans would siphon off less sick patients, leaving the public hospital at a disadvantage with a sicker Medicaid population plus the indigent persons not eligible for Medicaid or other public health insurance. This prospect was frequently referred to by clinicians, who worried that the hospital itself might be unable to survive, and that in its absence, those for whom the public hospital had provided care would go without.

> *Nurse #1: You wonder where, in a city and county where they don't have hospitals like this, what happens. Like in the south. Like if you're an Afro American in a racist southern town. What happens?*
> *Nurse #2: They must have some--public hospitals.*
> *Nurse #1: I think you just die. Some places don't have public hospitals anymore. They're gonna get rid of us...*
>
> ****
>
> *Nurse: Well, if we're simply capitated, um, we will have to find some way for people to be seen more efficiently than they are now. And, and, and we're not efficient. And that means that, well, let me back up a second. You know, I don't think that managed care is going to work. Uh, I don't think that our population is capable of having their care managed. I don't think the people who can't manage to tie their shoelaces are going to manage to be able to, uh, uh, take care of business. I think that we are a county hospital, and, uh, the county hospitals are, by definition, money-losing propositions. And, uh, that we will not be able to, that we will not be able to enroll, will not be able to--I don't think that we'll be able to enroll a large enough cohort of people who don't use the system as much to take, to pay the bills of the people that do. I think that we're going to end up with a large group of people who use the system a lot...*
> *Under managed care, I'm not sure that we're going to be able to continue this level of service for people. That is a question we have to think about.*
> *Int: This level--when you say this level of service, what do you mean?*
> *Nurse: I'm talking about the low level of service, the minimal level of service. The level of service that people sign in for so that they can get their social needs met. So that they can get a bus token. So that they can get a bag lunch. So that they can get a shower. Uh, so that they can get, uh, uh, some clothes. Uh, so that they can get to see the social worker. Uh, the reasons why people sign in for non-*

> *acute problems, because it's, it's either convenient or because the emergency room at City Hospital is the first portal through which people need to pass in order to become certified, uh, as being dependent.*

In this atmosphere, it is not surprising that "frequent flyer" patients have become the targets of provider frustration, resentment, and anger, that they are seen as constitutive of the "problem." Even though providers are keenly aware that such patients may have few other options open to them, their repeated visits (and the medicalizing collusion they often involve) and their dependency are here understood as a threat to the ability of the hospital to provide care for everyone and secure jobs for providers. The market orientation thus encourages adversarial relationships between providers and their poorest and most needy patients, and between payers and hospitals or provider groups which use too many resources in caring for patients. Lowenberg (1989) presciently suggested that the trend toward personal responsibility for health would contribute to demedicalization of problems formerly medicalized; the market-driven rhetoric of scarcity, it seems, may accelerate this trend.

Restructuring.

During the period in which this study was being conducted, a tectonic shift was taking place in health care (Estes & Binney, 1993; Estes & Alford, 1990; McCormack, 1988; Shortell, Gillies, & Devers, 1995). Responding to procompetitive changes in health care financing and regulation which were apprehended as threats to their future financial viability, many hospitals, including the ones in which I collected data, were in the process of "restructuring" their operations, and nurses were feeling

> *threatened, a little bit scared. I think everybody is because a lot of nurses will be, I think, losing their jobs, or be put somewhere else. And there's so much change here already in the last five years. [ED nurse]*

In both hospitals where I collected data, layoffs or nonfilling of vacant nursing positions had already taken place on other units. This affected care in the ED as nurses found it harder to find inpatient unit nurses when wanting to give report on an admitted patient; delays in making such reports meant time lost from ED work, intensifying the climate of urgency. Those providers remaining felt apprehensive and insecure (Kleinrock, 1995).

As insurance companies and other payers tighten their controls on providers and hospitals, and as hospitals shift from a community service orientation to the competitive, market-driven approach, providers struggle against feelings of alienation. Expertise in caring for other human beings is not easily reducible to "customer satisfaction." Providers' understanding of their work is often fundamentally not congruent with working on the delivery of "clinical service lines" for "contracted lives" (Shortell, Gillies, & Devers, 1995). The differences are not merely semantic. During one discussion of these trends, a nurse offered a brief, bitter summation of the increasingly "assembly-line" model of hospital care:

> *Int: Seems like health care in general has really changed.*
> *Nurse: Oh, absolutely, yeah. I talked my daughter out of going into nursing.*
> *Int: Really?*
> *Nurse: Yeah.*
> *Int: How come?*
> *Nurse: (softly) Because it's not fun anymore; it's all business. Move 'em in, move 'em out.... Well, see, nursing is no longer an art. (flatly) It's a job.*

"Fun," for this nurse, involved an engagement with patients--an art--that is more and more precluded by the press for increasing "efficiency" and the emphasis on "techno-cure" (Benner, 1994b, 1994c). As care is reduced to those technical procedures which are quantifiable and financially reimbursable, patients and providers often share an inchoate sense of frustration and moral distress. This nurse's bleak assessment was tellingly affirmed in a quote from a physician recently named president of another large urban hospital during a time of fiscal uncertainty, who defended the hospital against claims that care had deteriorated by saying:

> *There is no question that the art of medicine has suffered, because of the time we are able to spend with a patient. But the science of medicine has not suffered* (Quoted in Russell, 1995).

The "art" of medicine or nursing has always been an elusive aspect of these practices of commitment, predicated on interactions and relationships in particular situations: such caring is irreducible to procedures or general rules (Noddings, 1986). The healing practices have a long history of and conversation about this "art" and the moral traditions it embodies. This kind of expertise in practice cannot be quantified and charged for, but it can be (and has been) appreciated and needed by sufferers, who consult health care practitioners for healing and comfort as well as for cure. However, it is increasingly viewed as inessential, secondary to the technical procedures that are more easily standardized, measured, and billed, and those who would preserve it are made to feel that their concerns are retrogressive, sentimental; that they are trying to impede progress. Part of this stems from a view of caring as an individual, personal activity:

> When the word 'care' or 'caring' is used, most often it is thought of in psychological, individualistic terms--as a sentiment or attitude possessed by a private individual. Care or caring is thought of as a 'private feeling' and most often is thought of as a radically free choice--a self-possessed choice to care or not to care. Bureaucracies that set stringent limits to the timing and control of caring practices create additional barriers for doing highly contingent, relational caring work, thus reinforcing the individualism in terms of which caring is construed in our culture (Benner, 1994c, p. 141).

When caring practices are viewed in this way, as individual private behavior, the ways in which those practices are constituted and extended by communities are concealed. Nurses and other providers who want to preserve such traditions often feel forced to "go around the system" (recall the nurse in the last chapter who took time "out" to care for her patient) in order to provide care, inadvertently furthering the view of caring as an individual, personal activity and further isolating caregivers from one another. Engaged caring--especially caring for "bad customers" who do not have insurance coverage and "legitimate" conditions--thus becomes a furtive activity, carried on behind a dense curtain of competitive rhetoric that obscures the effects of bureaucratic and market forces on caregivers and patients alike.

Neighborhood Changes.

In addition to the "internal" changes wrought in health care by managed care and restructuring, the neighborhood and community outside both hospitals have changed. At Our Lady Hospital, a nurse pointed out that there used to be more houses around the hospital, and the neighborhood overall was more peaceful. "There wasn't the gang violence...You could wander out of here at five in the morning and be relatively safe, and not even people who live here feel that way now" [Fieldnotes]. Though they remember that there was violence even in the "old days," they do not recall retaliation being so common as it is now between rival gangs. "Now they're brutal; they're ruthless." The nurses have had to call police to break up fights between gangs in the ED lobby.

Even the police, however, are not as connected to the neighborhood as they once were:

> *Nurse: And the police are not as--I mean, many years ago, when the police were here visiting, we used to be able to con them into taking some of these people ["frequent flyers"] home if they lived really close. Now the only place you can get them to take 'em is detox. You wait hours for that. They're busy too.*

In earlier times, these nurses recalled, the relationships between ED care providers and other community service providers were more fluid and friendly; there was a sense of being united for a common good. The police "visited" the ED regularly, sharing coffee and stories. Sometimes these relationships even extended to socializing together in "off" time. Such a relationship between different sectors of social service providers can have real advantages, such as sharing information about resources, coordinating efforts to help individuals or groups, and mutual support. As social services needs have grown and as funding has become more scarce, however, such informal, collegial relationships have diminished as a function of each group trying to do more with less. This points up the potential for fragmentation, disorganization, isolation and inefficiency that can, paradoxically, be an unintended consequence of the press for efficiency.

> *Nurse: I mean, they may be out in the waiting room--now, just recently, the security officer said to me, she said, 'You know, this woman has been in your waiting room. This is the third night in a row. She comes in and somebody gives her a blanket and she sleeps there, and she gets up in the morning and goes to the bathroom and cleans herself up, and goes and catches the bus.' I said, 'Three nights in a row? Have we seen her?' She said, 'No, she hasn't been a patient here.' I said, 'Well, why is it she's here three nights in a row?' So I went out to talk to her and uh, she was painting this picture of afraid to go home because of domestic violence and this and that. But, actually, I, I never got to the bottom. She refused to give her name. She refused to talk. We gave her some shelter numbers to call, which she said she did, which I don't think she did. Uh, she worked at [local department store]. That's what she did. She'd get cleaned up in the morning, she'd go to work, and then she'd slum around [nearby shopping mall] all evening, and then she'd show up here about eight or nine o'clock at night, get a blanket, and go to bed. Because nobody threw her out. I mean, they go hiding in--I mean, if you've been out to our waiting room there's lots of places to hide that nobody would ever* <u>*see*</u> *you out there. ... Uh, so you don't have the* <u>*time*</u> *it takes to spend with these people to do that type of thing. I mean, it takes an exorbitant amount of time to talk to these people, to get them to trust you, to open up, to find out what the heck's going on. And you're always being pulled to answer the telephone, or take care of this or go do that.*

This nurse is ethically solicited by the woman's plight, but again time pressures and the tyranny of routine tasks intercede. This is a story with an ending that is morally unsatisfying; although the nurse gave the woman the shelter numbers, thereby fulfilling a minimal obligation to help someone in need, she understands that authentic "help" is predicated on something deeper than this kind of procedural response. Help, for this nurse, means offering understanding, being trusted, and connecting with others, all of which require time and patience. In the market model of health care, such a woman simply has no place: she is not even a customer; she is only a kind of shoplifter in the medical care supermarket.

Market-Driven Deterioration of Care Networks.

Communities of care cannot thrive and grow when they are deprived of the public reserves and support necessary to provide that care. Emergency care providers have always been considered providers of "last resort," but in the past there were either more supportive resources for referrals or a better system for linking people with helping agencies.

> *Nurse #1: I think the whole social system has changed. The homelessness, there's so many homeless the (inaudible). The crime, the violence, um, the fact that we don't have places to send you. We used to be able to put people in places where they would get care. The people (inaudible). And we used to take care of people, give them three meals a day and a bed and that's where they were and they did better and it was probably (inaudible).*
> *Int: Are you talking about like mental institutions or, or the hospital itself?*
> *Nurse #1: Chronic care places I think, that, um, you know. You go out and you go out to [Main] Street and people are walking all over, hallucinating, you know, they're--they just cannot take care of themselves. I mean, it just invites a whole bunch of other problems, you know, illness and, you know. So I think the whole social thing has changed. The whole --I've never seen homelessness like it is now.*
> *Int: How about in the ER itself? Do you think that's changed?*
> *Nurse #1: (pause)*
> *Nurse #2: Seeing more of it. I was thinking when I started on nights.*
> *Nurse #1: We used to discharge people and if they didn't have a place to live, we'd find them a place to live. You know, there'd be places for them to go to. I remember how appalled I was when we discharged somebody to the street. And*

> *then it just happened more and more and now it's, you know, no biggie, I mean, we just--*
>
> *Int: When did that, when did that start to change, because I seem to remember that this--*
>
> *Nurse #1: It used to be we'd find them a place and now it's just so hard to find a place.*
>
> *Nurse #2: I think it's higher volume. I mean there's no doubt there's higher volume of homelessness in the last 15 years. I mean.. think about the city 20 years ago. You'd drive down the street. You didn't see people sleeping on the sidewalks, and now you see it all the time. It's a volume issue.*
>
> *Int: And it's now sort of accepted as normal.*
>
> *Nurse #2: Yeah.*
>
> *Nurse #1: You're not as shocked now to see someone lying in a doorway.*
>
> *Int: Do you remember when this started shifting? I mean, do you remember having discussions about it?*
>
> *Nurse #1: It's been years, I don't know how many years but it's been some years. But I remember, I mean, I remember saying, 'How can you put this person out? He doesn't have any place to go.' You know.*
>
> *Int: And what did they say?*
>
> *Nurse #1: 'Can't keep everyone.'*
>
> *Int: Uh huh.*
>
> *Nurse #3: Well, there was more money (inaudible).*
>
> *(inaudible simultaneous comments)*
>
> *Nurse #2: I thought we took care of them because we admitted so many people with abscesses 'cause we knew they couldn't take their antibiotics on the street. We knew their situation.*
>
> *Nurse #1: Well, now they don't do that anymore.*
>
> *Nurse #2: And that's gonna be the trend.*

These nurses point to dramatic shifts in the moral boundaries of practice that trouble them, but against which they seem to have no convincing arguments. The rhetoric of scarcity has become its own answer to the disturbing questions it raises. The way what once was shocking has now become the everyday and accepted is disquietingly reminiscent of what Arendt (1992) termed "the banality of evil"; market logic enables a rational distancing by which moral issues are obscured. Wolfe (1989) notes that, in the market view which increasingly dominates all aspects of our common life,

> "tough-mindedness" toward moral issues is generally defended on realistic grounds, based on the argument that the economist, rather than ethically justifying people's behavior, is really only scientifically describing it (p. 33).

Thus policy decisions that result in supporting an industry of medical technology, rather than providing food, homes, and jobs in needy communities, are seen as simply meeting basic consumer demand for medicine, not as rationing care or providing for the "haves" at the cost of the "have nots." Administrative decisions that place the highest value on efficiency, expecting providers to do more, for more people, with less time and resources, are simply understood as a necessity of business, as responsible and rational adherence to the "bottom line," never as decisions the practical consequence of which is to deny care to poorer patients whose problems are more complex and more time-consuming. Practice decisions that render patients with technologically "fixable" problems more legitimate than those with chronic illnesses or social problems are interpreted as justifiable because of the necessity to be efficient. The colonization of health care by the market thus has a cascade effect from the policy level to that of the patient, perpetuating the profitable "medical cure system" at the expense of the health *care* system.

Consumers or Citizens?

Yet "to extol the consumer is to deny the citizen," as Borgmann (1992) has argued:

> When consumers begin to act, the fundamental decisions have already been made. Consumers are in a politically and morally weak position. They are politically weak because the signals that they can send to the authorities about the common order are for the most part ambiguous. Does the purchase of an article signal approval, thoughtlessness, or lack of a better alternative?...A consumer is in a morally weak position in the same way that anyone is relatively helpless in the exercise of daily decisions. Daily decisions are preformed by fundamental decisions. The fundamental and material decisions that have shaped the technological society leave little leeway to the daily decisions of the consumer (pp. 114-115).

The model of patient as informed consumer is thus doubly flawed: not only are patients often too ill to make "rational" choices, the interpretation of which is often dependent on caregivers as much as on individual choice, but the alternatives between which they are to choose have already been predetermined by decisions they had no part in making. For "frequent flyers," those more "fundamental" decisions mean that high-technology, "quick-fix" needs take precedence over low-technology or no-technology needs.

The practice of nursing has a deeply embedded moral tradition in which good care is based on understanding the patient's situation and putting the patient in the best condition for healing to occur (Nightingale, 1969). This understanding of the work is radically at odds with current market language, which suggests that "the goal is *to reduce the time it takes to make patients well!*" (Shortell, Gillies, & Devers, 1995, p. 147, emphasis mine), an aim which reveals not only a rather coercive-sounding understanding of medical practice, but an unjustified optimism about its capabilities, given our inability even to define "wellness" satisfactorily, especially in persons with chronic illness. Strange though it may sound, it is sometimes not cure that is most needed or even possible, but healing and inclusion in the human community. When nurses understand their patients' situation and yet feel helpless to provide what is really needed, the practice itself loses its meaningfulness as good work.

> *Nurse: It becomes a burn out situation. It's like having a kid who is not responsive to anything you help--I mean, you help them and then you end up, you end up, what's the word, um, becoming very frustrated and resenting them. And, I mean, admit it or not, health care people do resent these frequent flyers because it's a quote, unquote, perceived abuse of the system. But the fact is that these people are extremely desperate people, and it doesn't help them to get our negative feedback. It just makes them feel worse. And these people already feel so badly about themselves. It's the saddest part of the whole situation.*
>
> *But I--I mean, I've been there myself. There are times--I, I mean, I'm not pointing a finger 'cause I've felt that way myself. I don't feel good about feeling*

> *that way, but it comes up after a while and one becomes very frustrated. But the problem isn't just the patients. It's a big--layered, more structured issue.*

"Walking in any American city today," note Bellah and his associates (1991),

> one participates in a ritual that perfectly expresses the difficulty of being a good person in the absence of a good society. In the midst of affluence, perhaps with a guilty sense of the absurd wastefulness of the expensive meal, new blouse, or electronic gadget that has brought us to town, we pass homeless men or, often, women with children asking money for food and shelter. Whether we give or withhold our spare change, we know that neither personal choice is the right one. We may experience the difficulty of helping the plight of homeless people as a painful individual moral dilemma, but the difficulty actually comes from failures of the larger institutions on which our common life depends (p. 4).

Likewise, as this study reveals, it is difficult to be a good nurse or a good doctor in the absence of a good health care system, particularly in settings such as the ED, where so many problems of the medical system intersect with one other and with the problems of the larger social system. The "safety net" is too often experienced as a hopelessly entangling knot.

Beyond Medicine

Nurses, while searching for language that would allow them to reconcile the moral traditions of nursing with the economic pressures of contemporary hospital practice, were eloquent in describing what seemed to be missing in the life of the caring community:

> *Nurse: Well, it's beyond medicine. It has to do with our social structure. It has to do with the fact that, you know, how we spend our taxes and, and it has to do with the family structure.... I think when the family structure falls apart, or the support structure, it doesn't have to be a family, these people are loose ends and they have no support structure. And part of being able to maintain your health care and keep appointments has to do with your support system. And many of these people don't have it. And that has to go back to--*
>
> *A lot goes back to politics and where we spend our money and what we value and where we put our money. And the more that money goes out of education in creating--helping people to create families that work, um, you know, I have strong feelings about that. But then the other thing is, I think it's the*

> *American culture that we sort of fast track and we value very sort of superficial, titillating, moving around, making a lot of money things. And I think that even in the middle class America, since the 'fifties, that family structure is dissolving. And there are, um, family is the structure that people thrive in. It doesn't have to be a husband, wife, um, but it can be— a* <u>*community*</u> *structure—and the community has dissolved. And you lose a lot when that happens.*

What is lost is the sense of belonging to something larger than oneself, a fabric, a web that connects humans with one another in a common, meaningful life. This is, after all, the dilemma of modernity (Borgmann, 1987, 1992; Kierkegaard, 1846/1962; Taylor, 1989), but until recently, the health care setting was one place where remnants of that common life, including the exiguous moral language of public care for one another, were preserved and protected. Now, it seems, the relentless insinuation of the market into the lifeworld (Habermas,1987) has further decreased the space within which such a life can be imagined.

<u>The Almshouse Revisited</u>

The almshouse thus resurfaces as the ancient model for some sort of social structure that would meet the kinds of needs that now go unmet. This is not because the almshouse is an ideal, because it is not; it is because we have few other historical sites of public care on which to draw as we try to imagine a different kind of institution, one that might meet both medical and social needs.

> *Nurse: I think, you know, a lot of the reactions that we have [as] professionals, sometimes the frustration and what not, is truly that we're just not doing whatever it's taking to introduce some sort of degree of health, uh, and* <u>*true*</u> *caring. I think, maybe, conferring on these individuals and giving them a* <u>*true*</u> *means by which they can maybe make a change or turn their lives around, for any kind of a rehab[ilitation]. We don't have a system like, you know—*
> *Int: What would that look like?*
> *Nurse: I don't know. Um, it's really kind of funny. You know, you talk about allocation of health dollars and stuff, and I think some people would feel, you*

know, kind of better that, you know, it's like it's sort of like three strikes or something. I think from the medical end some people who are really Republican in thinking, you know, get so frustrated and stuff like that, maybe would give their all to people who had like three strikes, GI[gastrointestinal] bleed from bad alcoholism, you know, drinking and stuff like that. And then the third time they don't do the surgery, or, you know, millions of units[of blood], or, you know, put them in an ICU[intensive care unit] or something and just see if they heal on their own. That's what they do in Sweden.

Int: (inaudible) three strikes you're out?

Nurse: What would the social system look like if we were helping people? I got off on a different tangent, um, thinking about like from the perspective of health care workers who are really burned out on people.

Int: What if they get their shot and if they didn't do what they're supposed to do--

Nurse: Yeah. And I think, in a way, for some people who are Republican in thinking, that would be sort of a safety net and maybe even with, you know, like being that Republican in thinking and thinking you have three times, maybe even health care workers, and like they'd really try, and will really go ahead and say, 'Well, you know, you got this resource and this and this and this. And you know you've only got this one-- If this happens again, it's like going to prison for the rest of your life. You might really die!' You know, that sort of thing. And then-- ah, that sounds pretty immoral to me, but that's the way Sweden has handled the fact that they have such, you know, heightened sense of, uh, disease from alcohol over there. It's a cold country. Oh, yeah, there's lots of alcoholics there.

Uh, but anyway, because of that also within their whole social framework, they have truly decent rehab[ilitation] places. This is called like--live-in detox[ification] places where it's not just shake and bake and then you're out of there in three days and then prove for two weeks that you can stay off the sauce so that maybe we can get you in a program somewhere even though you don't have finances for it. I mean, we have programs for people who are, you know, chemically addicted one way or the other, like [drug treatment hospital], a private institution over in [city], things like that and they're very effective for people who A, have something for live for, um, you know, haven't like gone completely to the bottom--no job, no this, no that, [and B, have money].

But I think that ideally in a society, we need to have all of this money that we have funneled into kind of taking care of these people who flop outside and

> *end up flopping in here because of their alcoholism need a different kind of a flop house, so to speak, for true social rehab. Now, it would be an incredible amount of money for outlay, there's no question about it. But we have to make some investments, or--just like health care altogether will be, you know, an investment. I just think that we have to make some investments that are going to be worthwhile in the long run.*
>
> *And it seems to me that in our society we haven't been thinking about long-term; you know, we're Americans. We think so short-term. We don't think about 500 years from now. How are we going to like change the way we live, you know?...*
>
> *But--that's a whole other thing; it's--our society's really fractured now...I mean, we're, we're getting into a lot of social ills, a lot of problems, you know?*
>
> *But we have to restructure things differently. At least we could start with one segment of society and that would be the alcoholics; I think that would really save a lot of money in the long run. If we can't get prevention, do better rehab. This is costing a lot of money the way we do this. And it's really frustrating, too. Can you imagine if you had a center where people knew that this was what they were doing-- that they were attempting to really detox these people? What a completely different attitude, and what a completely different kind of a program that would be. You know, I mean, it would be totally different.*

Jack, the former "frequent flyer" whose voice was heard in Chapter Five, also imagines such a "totally different" place:

> *Jack: It would be beautiful. They have the space right over there right now, you know. They'd have a waiting list from here to New York. (chuckles) Ain't lyin'! They would. But can you imagine that? That would be the most beautiful thing God could ever wish for me. I'd die for that almost, you know that? Six months, you could help someone, really help them.*

This nurse and Jack, speaking separately and without knowledge of each other, have eloquently articulated a shared vision of a "different kind of flop house"--one that provides a longer-term commitment to helping those who are now the ED's "frequent flyers." Their alternative vision of ***true*** caring evokes the concept of the almshouse, whose functions are perhaps even less well carried out today than they were when institutions bore that name. It could be argued that at least when almshouses as such existed--coarse and inadequate though they were--their very presence affirmed the social legitimacy and complexity of the problems with which people came through their doors. Though they were confining, an institutionalized check against the vices of sloth and inebriety, their denizens were at least confined *within* a socially sanctioned and morally coherent (if not morally appealing) institution of the common world.

In contrast, the "homeless shelters" of our day embody a very different understanding of that world. Desjarlais (1994), in a richly textured phenomenological account, has called attention to the way contemporary homeless shelters, rather than exercising control through acts of confinement, exercise it instead through acts of displacement and obscurity, such as insisting that residence is temporary, requiring residents to leave the shelter during the day, and providing no private space for residents.[11] Such places thus serve to *exclude without* rather than to confine *within*. Although it could be argued that they still serve as broad social warnings against the vices, their status as institutions is in marked contrast to that of the almshouse. Whereas the almshouses were regarded as more or less permanent community institutions with a long-term charitable mission, homeless shelters are often located in temporary or seasonal quarters, the needs for which they were established implicitly assumed to be short-term. This is the "quick-fix" version of an almshouse, and it is no more effective in solving the deep-rooted social problems at the heart of urban homelessness than the "quick-fix" of medical technology is at solving the problems of chronic illness.

This is not the vision summoned by Jack and the nurse as they imagine *really* helping and *truly* caring. But their use of these qualifiers suggests that they see our

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[11] Elias & Inui (1993) reported similar findings in a phenomenological study of homeless older men. They also make the point that in a life characterized by what they call "lack of temporality," the ability to plan ahead (as for appointments with health care providers) is limited.

present way of doing things as somehow false, morally fraudulent. The nurse makes it clear that what she is able to do now does not often constitute what she understands to be *true* caring; Jack's emphasis on how people could *really* be helped suggests that what is offered now is not only inadequate, but also somehow inauthentic: a cover-up for the social unwillingness to help. The contemporary homeless shelter takes a single facet of a complex community problem--the fact that large numbers of persons have no home--and reduces it to a temporary aberration common to certain individuals, remediable through making homelessness itself unpleasant enough that they eventually either go elsewhere or find themselves a place to live.

> *Jack: This place is empty at night. Now, tell me, if they get--they're gonna do what they're doin', no matter where you put 'em. Granted, a hospital isn't a social club. Is it? I have known people that come here every morning and get the garbage that people leave after they eat. [Mhm.] They catch it off that belt. Now, do you think the seagulls and the pigeons know what they're doin'? Those people know what they're doin', and they eat just about like those pigeons and seagulls, but they're human beings. Huh. This doctor wouldn't put his tray down, he followed it in. Now, you know, that's a cold man. Heh-heh. That's a human being? You know, he is! The patient and the doctor. And, you know, he was just that--arrogant about it, lettin' the guy have a piece of toast and some eggs, or whatever; yeah, it was garbage. [Hm.] You know, I, I know it sounds bad, but they're not gonna do what I said, but--they could do* <u>something.</u>
> *...I mean, let's be real; they don't want to do a damn thing, and they're not gonna. [Mhm.] Unless somebody gets--serious. No one has that drive any more.*
> *Int: No one has what?*
> *Jack: That drive, you know. Those days are gone. You know.*
> *Int: I don't understand what you mean, that drive.*
> *Jack: Go out and save these kids. And these old people, that are sick. A lot of 'em --don't have anyone! I don't have anyone out there; if I got sick, I'm on my own! I freeze to death; I'm the one that's out there. I did have family that cared, and I didn't know--back then, you know, you get older, things do change. [Mhm.] But these people--they get scared--you ever freeze to death? Or get hypothermia?*

> *It's, you know, that's beautiful, I mean, it doesn't hurt, 'n' I wouldn't recommend it as a (inaudible), I mean, it's peaceful; it's not like burnin' to death.... some people don't have any place to live at all! [Mhm.] and the shelters are dangerous. They have no medical care there; they put em in that [alcohol patrol] van, and there they are! Go across the street, get a six pack, then you take off your shoes, call em up to come get em. And they get a doctor's slip, one of 'em stays and answers the call--come on, it's a game! And--and, they get caught, they get thrown out, they can go back in sixty days, or go to [adjacent county]. You know? That's the name of that tune, and it's a lotta money. These people are scared on the streets. There are men who worked all their lives--I swear--eating off that belt... But they are proud of it because they didn't steal...They are human being survivors, and gold star cause they didn't go to jail. All of 'em been pushed everywhere but off that rail. [Mhm.] Really!*
>
> *And I looked at that doctor, I was gonna say something, but I...I told the doctor, that's an unbalanced meal you just ate.*

Paternalism or Abandonment?

Issues of social dependency cannot be discussed without addressing paternalism. Paternalism has a bad name in contemporary Western culture; it is associated with male hegemony, loss of individual autonomy, and intolerance of differentness. Yet we continue to design and carry out social policies as though our options were limited to paternalism or anarchy. Intent on controlling social deviance, we relinquish opportunities for understanding and care. Determined to avoid treading on the right to individual self-determination, we relinquish the social responsibility to be our brothers' keeper. Both positions essentially perpetuate the view of the other as wholly other, the first by demonization, the second by abandonment.

Thomasma (1984) argues that "life itself might be more accurately described as a web of interdependencies than as an atomic conglomeration of autonomous entities" (p. 913). He asserts that beneficence, not paternalism, should be emphasized in medical decisionmaking. Thomasma acknowledges the damage to autonomy inherent in paternalism, but denies that beneficence is (or must be) paternalistic. Acting in the best interest of the patient, he argues, need not necessarily mean limiting the patient's autonomy; that autonomy is already limited by illness or injury and, further, by our interdependent human condition. Caregivers in this study wrestled with these issues on a daily basis, especially with homeless and alcoholic patients whose care seemed inadequate.

> *Physician: They started calling them homeless, which I think is a mistake. Because I think there's a very unhomogenous group of people. I mean, there's homeless families who have a social connectedness that's gonna help them. Then there's, you know, people that are substance abusers who happen to be homeless. And their primary problem is social, lack of social connectedness, and their substance abuse. That's their big problem. They also happen to be undomiciled, but uh, to sort of give them, we give them too much dignity. They need to be much more, uh, when they get that deteriorated state we need to be more paternalistic toward their care.*
> *Int: And what would that look like?*
> *Physician: Um, if you go to other counties to see their, their office of conservatorship is much more active now.... And the point, the reason to, uh, hold someone against their will and treat them is that they have to be homicidal, suicidal, or gravely disabled. And the gravely disabled aspect of that is relatively open to, open to, uh, interpretation. You can interpret it and say that someone who's psychotic and living in the streets, homeless, uh, getting sores from living and being hypothermic, is gravely disabled by their disease, and should be treated... [In this county] we believe that can be a lifestyle choice, and we don't put that patient under a hold....*
> *Int: Have you tried to do this?*
> *Physician: I've tried with some of the patients who come in with, you know, repetitive--most commonly combined medical, um, and, uh, psychiatric problems, substance abuse users who are significant diabetics--. There's one gentleman, whose name escapes me, who just didn't take his insulin and drinks a lot. And every time he comes in, he's in DKA[diabetic ketoacidosis]. You do this once a week for, you know, a couple of months and you decide that this may not be the way to go, that he's unable to handle his affairs with this disease, or whatever. And maybe he should be best conserved...*

> *Now if he were in another county, it would be a different question. whether they have a lower threshold, whether they have more money to be able to conserve these patients, whether they have more money to be able to have an office of conservatorship that can do this.*
>
> *Int: Is that a factor? Is there like a lot of research that's involved in that?*
>
> *Physician: I think it's a philosophy. I'm sure there is. I mean, obviously... you have to have a lawyer on both sides, because of the court process and then you have to conserve them. In other words, you have to pay for his [long term care institution] stay for the rest of his life. And also it's rather difficult for patients who are intoxicated. You know, so you're saying that they are incompetent, where you wait 6 hours and they're no longer incompetent. They're just in withdrawal. And so they gain some competence. If you put them in [long term care institution] for a month, and you give them three squares a day, and you make them sleep well, then they look like a regular human being after four weeks, and you go, 'Well, why is this guy conserved for the rest of his life? Um, it, you know, maybe he should be let out.' And then he probably should be at that point, with good follow up...*
>
> *To be honest, [east coast U. S. city] didn't conserve them, either. They had the problems just starting, back then, but--They didn't really deal with it either. And in [southern U.S. city] it wasn't as big an issue, nowhere near as big a problem. And I think [southern city] because, uh, we didn't get so many transients. Everybody had a family.*
>
> *Int: Everybody had a family?*
>
> *Physician: Yeah. You know, and that's--and if you talk to these people [here], you go, 'Well, who can take care of you tonight?' You know, there's no one. There's no family. There's no friends. There's no--maybe the manager of the hotel is best they can come up with. You know, they're incredibly socially disconnected. That is their major problem, you know. Lots of, you know, lots of alcoholics function reasonably well, with families and social, you know. These-- they've lost that-- totally. So [southern city] didn't attract any transients. Even though you were a ne'er do-well forever, there was always somebody's sofa you could sleep on, or--something.*

"Giving them too much dignity" seems here to mean attributing a level of agency and autonomy to patients that they are unable to sustain given their condition and their social context. This physician reminds us how intact families and social connectedness can dissolve many of the problems of trying to balance paternalism and absolute autonomy, since having families, being connected, automatically means a qualified kind of autonomy. In families, we see a version of autonomy in which individual agency is tempered by some level of respect for, responsibility to, and recognition of the needs of others. Lacking the ability to offer such family support structures, however, medical care providers are forced by the limitations of the larger system--and the absence of a larger caring community--to choose between paternalism and abandonment, two equally unsatisfactory alternatives.

> *Physician: Ultimately it would be cheaper for us and for them to care for them in a sort of more paternalistic manner. Uh, and, you know, like if you came in this hospital and you had a leukemia, regardless of your insurance status, we'd spend the next $100,000 on your chemotherapy over the next year 'cause you have a good chance of dying of leukemia in the next 5 years. But we know these patients who are chronic, street alcoholics, the 5-year mortality approaches 80 percent. And that's been well-documented by this hospital. But we don't go out and spend the money to do that, even though it has the same mortality as the leukemia.*

This physician points to the moral economy of decisionmaking in allocation of medical and health care. As will be discussed further in the next chapter, our society's alcohol policies are often inconsonant, and they reflect implicit judgments about social worth and its relation to economic productivity. Those like chronic street alcoholics whose potential productivity is viewed as questionable need care, and failing to care for them, as this physician asserts, is possibly as expensive as providing that care. However, while these patients come to the ED repeatedly seeking help, ED providers simply cannot provide the kind of help that is needed.

Both paternalism and autonomy, taken as absolute principles, perpetuate a self-understanding of human beings as essentially rational engineers, either engineering the fixing of others' social inadequacies, or engineering the fixing of our own inadequacies, all by ourselves. One prejudices the sovereignty of the state or its designates; the other prejudices the sovereignty of the autonomous individual. Neither satisfies our needs for both connection and freedom. Elshtain (1994) suggests that an ethic of responsibility in which both the sovereignty of the state and the sovereignty of the individual are limited is required, an ethic characterized by accountability to others within an atmosphere of mutual interdependence and recognition of finitude.

A communitarian ideal need not, as some have suggested (Young, 1990), mean the denial or repression of difference. Young's argument is that such an ideal has no room for differences within and between subjects. She points instead to an ideal of city life, within which strangers remain strangers to one another, yet acknowledge and respect differences. Her vision of the unoppressive city is one of "openness to unassimilated otherness" (p. 319), and I think she is right in pointing to the city as a place where differentness can be experienced as part of the pleasure of the public world. My concern with such an ideal, in the context of this study, is that it may champion difference at the expense of commitment to a struggle to see the other, creating a politics in which mutual exclusion substitutes for the communitarian ideal of mutual inclusion. The distinction that is important here, I think, is that between inclusion and assimilation. To be included, to belong to a community, need not inherently mean either a loss of individuality nor a totalizing sameness.

Paradigm Case: Charley

> *I'm not no doctor, but I think one of the greatest healing powers in the world is a person when he starts feeling good about themselves, and caring about themselves, you know?*

Charley, a 58 year old man who volunteers at the hospital, is a key resource person for the institution's "stop smoking" programs. He lives in a senior housing residence on a social security income of about $700 a month; he has five children, four grandchildren, and one new great-grandchild, all of whom live in the area. He says he does not have a wife, but does not offer any information about the mother or mothers of his children, so it is unclear whether he is divorced, widowed, separated, or unmarried, but he does not now have a spouse. He volunteers at the hospital between four and five days every week, and, like Jack, is highly regarded by staff.

Not very long ago, Charley was a "frequent flyer" who came into the ED regularly with problems related to his chronic lung disease, often precipitated or exacerbated by smoking, heavy drinking, and drug use. "I wouldn't go to bed if I didn't have me a tall can of beer, and a half pint of Gilbey's gin," he says now of those days. He required endotracheal intubation for support of his pulmonary status on eight different occasions. On one occasion,

> *I came in one time and, uh, I was, uh, having trouble breathing. And the doctor kept trying to tell me to do something. I kept tellin' him, no! This, that and the other. And then they was trying to put a tube down me, you know. And, for some reason, I don't know what it was, I guess the alcohol in me and the drugs, all that stuff, had me just resisting them, you know, fighting them. And, uh, so they gave me a shot of something in the IV, and I tried to snatch the IV out, you know. But then the next thing I noticed, they, they finally got something in me that-- plopped me right down, you know. And, uh, I'm laying on the thing. I'm trying to move my legs, but I can't move. And so I'm, I'm trying to--and this doctor. I know his first name's Larry. And I remember after they took the tube out of me and everything, I told him, 'You know what? When I get out of this bed, I'm gonna kick your ass! ' (laughs) And, you know, and right today when I see him, I always say, 'Hey, Dr. Larry,' you know, I say, 'Man, hey-- thank you,' you know.*
> *But like I say, through all this other drinking and, you know, a bunch of crap in your head, you know, you could-- that's why I say, those doctors go through a hell of a lot down there, I think.*

Charley now sees his past as an essential part of his coherent narrative about himself. His life now is made more meaningful by those past experiences of struggle against dependency on substances, and he sees his current work as a way of making sense of and atoning for his past. I ask him if the ED staff had an impact on this change.

> *Int: Did anything that anybody said or did in the emergency room make a difference in some way, at that time, to you as far as --changing? You know, like the people down in ER are always saying, 'Stop drinking, stop smoking, stop this,' you know. But does that do any good? Or do you think, uh, is there anything else that they say or do that is--it could--?*
>
> *Charley: Hmm, well. (pause; appears thoughtful). I mean, it's, it's, it's saying that, to a point, to a point, and uh, showing a feeling of caring, of concern. [Mhm] You know what I'm saying? It's like that one nurse, Vera, down there, now, I came to ER so many times, that she would tell the doctors to start giving me [my breathing treatment] immediately.*
>
> *Int: Yeah, she knew you.*
>
> *Charley: She goes, 'Okay, here comes Charley; hey, doc, give him 125 of Solu-Medrol,' you know what I'm saying. 'And I'm going to fix him up an Albuterol nebulizer.' And boom, you know, like, and maybe he'll say, 'Okay,' you know. 'So, well, you know him?' 'Yeah, he's a frequent caller.' And they were starting to chart me down on the chart, you know, gave me the nebulizer treatment. Sometimes I'd be okay and I'd stay there maybe 7, 8, to 9 hours. I been out maybe 12 hours in the ER in the observation ward. And I'd go home, you know. So it was a lot of times. One year. One year, I came to City Hospital 12 times, was admitted to the hospital eight times. In one year, okay? And then another time, in a 12-month period of time, I think I was <u>admitted</u> in the hospital 12 different times.*
>
> *Int: So you really were a frequent visitor down there.*
>
> *Charley: Mhm. [affirmative]*
>
> *Int: So you thought Vera cared about you, though. It wasn't just doing her job?*
>
> *Charley: Well, at the time, she was like doin' her job but it was a thing like, hey, man, this lady, you know, has a concern about <u>me</u>-- But it was this idea I was so regular, you know what I'm saying, to the point that she, in a sense, said, well, 'Hey, you know, I can recall what helped this guy.' You know, and she would tell me, 'Charley, you need to quit smoking.' And I'd say, 'You still smoke.' And she'd go, 'Yeah, but I ain't got no breathing problem, neither.' (chuckles) You know.*

Charley does not answer my general question with a general answer; he switches quickly to an engaged narrative about his relationship with the nurse. What Charley remembers is not so much the content of the messages health care providers gave him; it is the "caring" and "concern" they showed him. This caring, in turn, was very much related to his status as a "frequent caller;" as with so many of the current "frequent flyers" I interviewed, being known mattered to Charley. The portion of the story where Charley confronts the nurse about *her* smoking thus reflects more than mere resistance to a recommended behavior change; it also signifies that they have a relationship of sufficient closeness and trust that he knows he can cross the patient/professional boundary in this way without fear of rejection and exclusion. He recognizes the nurse as also in need of and worthy of care.

Jack, another former "frequent flyer" and current volunteer, whose story was heard in Chapter Five, told me a story of an episode that bears a distinct resemblance to this one. Jack experienced a kind of epiphany one afternoon when he saw, drinking in a bar, a doctor who had earlier told him to quit drinking.

> *I was sitting in the same bar one time, and 'Hello.' 'Oh, hi, Mr.____.' <u>Mister</u>, you know, it's 'Mister, you know, ____, you gotta stop this, you're killing yourself.' And the guy's an alcoholic too! Or worse. I know he's not lyin' to me, obviously very bad day for me. (chuckling) You know, we both knew he wasn't kiddin'. And I realized he was right, uh-huh. And uh, he since has stopped drinking. And I don't know what he's doin', really, with his profession, but--you know? He was honest with me. I figure, they'll all tell me that, it's their job. Here's a guy with the same thing. And he'd tell me, don't be ashamed. I said, 'I'm not; I'm scared, that I can't stop. I can stop drugs, but this crap I can buy for ninety-nine cents called Thunderbird has got me walkin' around without shoes.'*

The realization that even the health care providers who kept telling him to stop drinking were vulnerable to the same kinds of problems seems to have helped Jack move from the patient role toward an engaged helper role, helped him define a hitherto unrecognized boundary of his identity in some way. The act of reaching out can transcend status barriers and help redefine a self of connection. Where previously, Jack's addiction framed his identity--and helped him cope-- within a world of differentness and alienation, the helper role allows for the possibility of connectedness with others *in spite of* such differences. It becomes a bit safer to allow oneself to care when one is not isolated, regarded as wholly other. The story of seeing the doctor in the bar is one of recognition of both the limits of medicine's magic and of common human frailty in the face of death and aloneness.

Charley offers as another example of caring and concern a nurse in the clinic who is "still my favorite nurse today." He brings up her name as he talks about how many people's lives he affected by his previous ways:

> *Charley: I think I affected a lot of people's lives. Like when I was a drinker and a drug abuser and, you know, and I was doing different crazy things, you know. Even coming into the hospital and giving people bad times, you know. It's like this one nurse out in the medical clinic, Terry, I've been knowing her since she started working here, you know. And from day one, and, and, and I used to miss doctor's appointments, come in when I wasn't supposed to come in and then demand I be seen. You know, I mean, I mean <u>demand</u>, you know, it would just be, you know, like--after I look back at it sometimes, and I say, boy. You know, 'cause it was just total--I mean, stupidity, ignorant, whatever you want to call it. I was a real --jerk. Best way to put it, okay?*
>
> *And, uh, even Terry, she used to--she's the one who first got me to the Stop Smoking class, you know. Because, uh, this doctor named Williams--he was my doctor then at that time. And Terry was his nurse. And I would come into the clinic. And he would say, 'Charley,' you know, he would tell me, 'you need to quit smoking. You need to quit smoking. You need to quit smoking. You need to quit drinking.' I'd come in and, uh, I'd get the whole waiting room drunk, intoxicated, I'd be so--you know, the smell'd be so bad, you know? And I might*

have a bottle in my pocket, go in the bathroom in the clinic and take a shot, you know? And then--you know, and just-- couldn't hardly breathe, too.

And Terry said, 'You need to get in my Quit Smoking class.' So I said, 'Okay.' I came to one class and no more. So six weeks went by. And she said, 'I got another class. Do you want to come to my class?' 'Yeah.' So I think I missed the first class and she got on me about not coming so I came and I did about 3 weeks in a row, and didn't come back no more. And this process went on for like about 2 years, 3 years. Okay?

And, but she kept on talking to me...she was a nurse that was always there for me. You know? Even when I come in--'Man, I don't feel good today, Terry, I need to see a doctor.' 'Okay, let me see can I--get you a doctor,' you know. And she was, you know, uh--'Terry, I ran out of medication.' 'Okay, let me get a prescription for you,' you know.

And then I got in her class and I decided to go through the whole thing. And this was when I was going through the process of saying, hey, these docs are going to get tired of me coming in here. This doctor done warned me, this is my ninth trip in being intubated so, hey--man, what else do it take? You know. You know, is it gonna be <u>*death*</u>*? No. Huh-uh, I'm through.*

So I went through the whole process, and with her help and, uh, by this time I got another doctor, a doctor by the name of Dr. Jerry McDonald, and his help and a lot of other good people in the hospital here, you know, I managed to become a non-smoker.

Int: Well, now, what was different about her than about, say, some of the other nurses that made her stand out?

Charley: Made her stand out?

Int: Yeah. What was special about Terry?

Charley: Can I use a bad word?

Int: Sure.

Charley: Puttin' up with my bullshit.

Int: Huh! She didn't let that phase her.

Charley: No.

Int: So other people wouldn't put up with you? What did they do that was different?

Charley: Well, they'd probably ignore me, or-- and make me more angrier, until I'd become more hostile toward them, you know. And, uh, excuse the expression

> *again, that I would consider everybody in the room a bitch. You know what I'm saying? And, uh, but Terry was always like --I don't know. She seemed like, 'Well, Charley, you know you missed your other appointment.' You know, and it was like, you know, 'We, we care about you, but now you got to start caring for yourself, you know.' And, uh, I don't know. And she's still my favorite nurse today.*

Terry's persistent concern over a period of years was not merely an attempt to control Charley by getting him to change; it was evidence of a belief in his possibilities. The way Terry did not allow herself to be drawn into a power struggle with Charley, but tolerated even his "bullshit" while continuing to encourage him, preserved the possibility of a relationship based on mutual recognition and trust rather than on control. This story points to the way others' acceptance of a person as they are in the present is the necessary prerequisite to personal change in the future.

It also reveals the inadequacy of the "quick fix" approach for patients such as Charley and the others profiled here. If there is transformation, it is not often a temporally linear process as so many models of helping would have it; it is a circling, an often wary testing out of new forms of trust in oneself and the other; a process characterized by often infinitesimal, almost invisible increments of emerging possibilities. It is not a process of applying some standard treatment that will "make patients well;" it is a process of letting the person learn to trust in healing.

Charley sets up this important story of his gradual change by noting that he "affected a lot of people's lives," especially those whom he now identifies as having been most important to his recovery. This is on the one hand a regret for the suffering his behavior caused others, but in another way it is also an affirmation of connectedness. Experiencing ourselves as affecting the lives of others, even if only in an apparently negative way, opens us to the "ethical demand" (Logstrup, 1971) to respond to those others. The process, as the last chapter attempted to show, is not one-sided but continual and shared. As others trust us enough to reveal how we have hurt them, we are solicited to respond. Those whom Charley feels were less helpful, in contrast, would "ignore" him or become confrontive. Each stance sets up barriers to trust, the first by rendering the person invisible, and the second by rendering the person an adversary. Both exclude.

Charley's family also persistently urged him to change his habits and drew him closer by reminding him that his suffering was also their own.

> *Charley: My kids pestered me all the time. My youngest son, you know, he, he looked at me one day and he told me, he said, 'Man'--and he had tears in his eyes, you know? He said, 'Man,' he said, 'Why, why do you do us like this?' And I'm saying, 'What's you talking about, why I do you like this?' He said, 'Look at you. You're sitting there with a puffer[inhaler] in one hand, and a blankety-blank Camel in the other one,' you know what I'm saying? 'Puffing off the puffer and dragging on the cigarette.' He said, 'And tomorrow you'll be out there in the hospital and we'll all be running around here [saying] boy, is our Dad going to live or die?'*

Children, who have not yet developed the masks of convention whereby we "settle down cozily in mutual agreement about something irrelevant" (Logstrup, 1971, p. 20), are able to prod us out of our isolated subjectivity and remind us of our connection with others. For Charley, who tells several stories about his children's concern for him, including one where they replace the tobacco in his cigarettes with bathroom tissue, his children's efforts were part of a persistent, gradually more penetrating, "combination of all these things" that helped him believe he was worthy of care and capable of change.

> *Charley: And so it made me say, well, hey, you know, let me start and get myself together, you know, because--and like I tell all these doctors around the hospital, you know, 'Hey, man, I want to thank you.' You know what I'm saying? They said, 'For what?' 'For not giving up on me.' Because I, I say, I know it's got to be frustrating, you know what I'm saying? You see a guy here on Monday. You're saving his life, and getting him together, you know what I'm saying, and 2 weeks*

> *later, he's back on the streets again, breathing all right. But then 4 days later, here he's back in your trauma room again, you know. I said, 'You got to say, well, what'--the doctors say, 'What the hell are we doin' this for?' [Mhm.] You know? I said, 'I'm just thankful you guys didn't just throw your hands up and say, hey, you know, don't break your neck, cause he's gonna, you know--' (pause)*
> *Int: 'He'll just be back doin' the same thing.'*
> *Charley: Yeah, right.*
> *Int: But somehow they didn't.*
> *Charley: They didn't. They didn't give up on me, you know. And, uh, I'm very thankful for them. You know, I'm thankful for--like I tell people all the time. I say, well, you know, everything has its problems. A lot of people say, 'Well, City Hospital, you know, you go out there to the emergency and this and that--', but all you little minor cases like a cut finger: yeah, you know, you might have to sit there for a couple of hours, 3 hours, you know. But think about those people that come in between you. You understand what I'm saying? With the heart problems, the major car accidents, on life support machines, that they saved down there. And there's a number of people they've saved down there. And I'm one of that many numbers, that many hundreds, you know. And I'm very thankful to them, you know. And, like I tell people, we have people in (city) who should be very proud of our trauma center 'cause-- they're good. They're good. I mean, I know they're good.*

As Mike did earlier in this chapter, Charley here alludes to an experience of the ED as an institution of "good," and like Mike, he understands himself as part of that good, as "one of that many number" whose rescue constitutes the living accounting of that work. Charley experiences himself as part of this community of care, not merely because of the volunteer work in which he is now engaged, but also because he was among the rescued, among those on whom society did not "give up." The ED is interpreted as an institutional manifestation of the community's invitation to inclusion; he feels proud of "our" trauma center because he is now part of it.

When I ask, Charley offers some suggestions for caregivers who are dealing day after day with "frequent flyers" in the ED:

> *Charley: Well, only thing I can say is try--like myself, uh, I know we're a pain in the neck, a pain in the ass, really, okay? And I know it could be frustrating to a doctor. I've even told them, hey, I know it's got to be frustrating. Just like Dr. B. I talked about. You know, I mean, here's a guy you have worked hard on, to save, and he looks up at you and tells you, man, when I get up, I'm gonna kick your ass. I mean, you know. The only thing I can say, is be like good Dr. B. did. Look at me and pat me on the hand and say, 'Okay, Mr. Smith,' you know...*
>
> *And knowing that hey, sometimes something happens to these patients. It's not the real them sometimes, some of them. Some of them, it may be, but just don't try to lump all the problems you get from the patients as one big problem, you know, and continue to do a good job with that patient. And I'll be willing to guarantee, if a doctor show that kind of feeling and--to a (inaudible) patient, they're gonna come around.*
>
> *Int: If you what? I didn't--*
>
> *Charley: To show, you know, that he's caring and trying to, you know, persist--you know, <u>be here</u>. You know, like I've seen some doctors, you know, and maybe they might have done me like that, I don't know. But I've seen some doctors down in the emergency room where a guy might be a little bit out of control, you know, but it's way like, 'Hey, you know, I don't give a shit. You know, you can lay here and die if you want to, you know.' I mean, to express that verbally [Mhm.] and, and in actions, it's not bettering the patient's condition. It's not bettering your attitude, you know. And it's not making the whole atmosphere, environment any better, you know.*
>
> *So I'm just saying, hey, just try, sometimes, just like try to ignore some of that stuff, you know, you just-- Like, like I know you probably have to put on a human shield, a bullet-proof shield, when you come in here, with all the hostility you're probably going to get from the patients, you know, and especially in the city emergency room, because you get everything in there. 'Cause I've been laying up in the emergency room myself, again, and I've seen patients come in there that I've wanted to get up and go over there and bop on the head, you know.*

Charley here offers an informed account that moves gently back and forth between the perspectives of patients and the perspectives of caregivers. It bears an uncanny resemblance to Jack's discussion in Chapter Seven of how his volunteer work had taught him "to be kind in some situations I don't understand." It is an account devoid of blame; it invites caregivers to understand and to be understood. It asks caregivers to remember that the estranged circumstances in which patients sometimes find themselves can cause them to lose touch with the "real" person within, the person who longs to be welcomed, comforted, included, who belongs, underneath it all, despite differences which cannot be discounted or denied, to the human community. It also extends sympathetic understanding to the providers who must deal with the alienated and difficult patients they see. Charley's account beckons caregivers to "be here," to stay engaged with their patients as persons by accepting them.

> *Charley: I mean, you know, just treat them, like I was gonna say, treat them all as a human being, you know, not as a homeless, or this or that or whatever, you know. See. But just treat them as another human being coming here. And, and, and the same way that you want that human being to be treated if it's your mother or father. You know? [Mhm, yeah.] And I'm pretty sure, yeah, you'll feel a little better by it.*
>
> *Because, I mean, I look at my life now. Uh, I look back at my past life, like I say, you know. Uh, but, at one point in my life, you know, I may have had a bigger income, you know what I'm saying? And more money and all that jazz. But then I look at now. I have about a third of the money that I was making then, maybe a fourth of what I was making then. And a smaller apartment. [Mhm.] But I'm happy. You know what I'm saying? And I feel good. You know? That's, that's my main thing. You know, like I say, you might do some things, and they might not be as great and big, but it's how you're gonna feel about it, you know... And, uh, you might not think it does but then once you experience it, you'll see. It's, it's a good feeling. And it means a lot to you, too.*
>
> *Int: You mean as a patient?*

> *Charley: As a patient. As a patient, you know. Because, I mean, feeling good about yourself, and feeling good, you know what I'm saying? And doctors and nurses have this ability to project this onto people, you know? Because, like I say, the nurse Terry; Doctor Larry; you know what I'm saying?*

Here Charley articulates an ethic of public caring that draws on the model of the family. Like the nurse who tried to think of patients as "someone's child," Charley links family caring with the public practice of caring in the ED. This is not because Charley seriously imagines that every person a caregiver sees will be literally regarded as the caregiver's parent, which if it were possible would render parental relationships meaningless, but because caring practices have been so thoroughly relegated to the private sphere that we have sparse models and language for public care. The ED cannot be a model for public care in isolation from a wider community. We have a cultural confusion about the boundaries between people in relationships of community and those between people in family relationships that saddles health care providers with trying to attain an impossible ideal.

Yet caring itself is possible and significant, especially if we remember how small acts like calling someone by name can have a cumulative effect. Engaged caring, as Charley points out, can do as much for the caregiver as it does for the cared-for, and stands as contrast and challenge to our culture's emphasis on economic worth as a measure of social worth. Such caring does not pretend to omnipotence; it involves merely "doing your best" and trying to see persons as human beings.

Charley now experiences himself as someone for whom things matter, because he now experiences himself as both caring and being cared for. He feels himself part of something larger than himself; he feels included, involved. This was not the case when he was a "frequent flyer":

> *Charley: Because, see, I didn't care about myself, to a certain extent, and I didn't care about the next person if he lived or died.*

> *Int: You didn't care about who?*
> *Charley: I said, I didn't care about the next person neither, if he live or die, you know? I mean, so, but, hey, you know, I didn't care, you know. And, uh, now, you know-- I feel good about myself. I care about me. And I care about other people.*

This ethic of care is worked out in practice through Charley's efforts with the stop smoking program.

> *Charley: I went in one lady's room and she started, 'I don't want to quit smokin' and yeah, yeah, yeah...'. I said, 'Whoa, lady. Whoa, whoa, whoa.' She said, 'What you mean, whoa, whoa, whoa?' I said, 'You gave me flashbacks.' ... 'What you mean, I'm giving you flashbacks?' 'I remember, I can just see myself laying in that same bed you're in, and I probably was in that bed one time, sayin' the same thing, doing the same thing you're doing, and still doing.' 'See, you don't know what I'm doing.' And I said, 'I bet you drink alcohol.' She said, 'Sometimes.' I said, 'I bet you use heroin.' And she said, 'Well, how do you know?' I said, 'Well, I used to snort. I used to lay in that same bed.' You know, and I said, 'And I used to act just like you're acting right now.' And so she said, 'Sit down. Let me hear what you got to say.' And I still remember her name. Her name was Bettina Jackson. And then she told me, she said, 'Yeah, well, I think I'm gonna look into this.' You know, then she finally listened to what I'm saying, and I told her, you know-- And then the next time I saw her, she had went over there and got on the methadone program. And, uh, and she came down, and she said, 'I'm glad you came and talked to me. Made me stop and think for a minute.' I said, 'Yeah, well, thank you. Look what it takes sometimes,' you know?*
>
> *But then, like I say, when I go to people, I don't just go in there and tell them about all my problems and everything else to nobody. You know, I just go in and listen to them and then if something relates to it and I just tell them, 'Hey, you know, sometimes, you know, you have to think about--' --like I say, 'cause I been there-- It's not like me telling you something that I don't even know what it is. You know what I'm saying? I can define all the symptoms to you. I can take you to the holes you been through already and take you to the ones that you gonna have to go through.*

Charley's story of engaged caring demonstrates how caring can never be reduced to technical procedures. He makes this clear in the second paragraph when he explains that he doesn't always share this much about himself with everyone. Caring is always about the particular; it is not generalizable. The kind of ironic self-disclosure in this exchange, the gentle but confrontive stance he takes with this patient, cannot simply be taken from room to room like a medicine cart; it works here because it interrupts the patient's habitual strategy for dealing with strangers and sets up an opening within which trust can occur. It is not based on formal knowledge about how to teach people to stop their addictions; it is based on experiential understanding and emotional attunement in the situation.

Charley also expresses an experiential understanding of the limits of autonomy and control.

> *Charley: There's got to come a point, you know, that you think that you got control of your life, but you ain't got control of your life. You know? You do not have control. That little monkey inside your brain that tells you that you got to have a cigarette right now, you know what I'm saying? Because there's been times that, man, my knee been hurting, you know. And I said, 'Oh, man, I don't want to smoke a cigarette.' And then I'll say, 'Oh, man, smoke a cigarette 'cause it'll make your knee feel better.' You know, see? Or, 'Man, I got a problem. I'm stressed out.' 'Smoke a cigarette, man, you'll be all right.' You ain't gonna be all right, you know? [Yeah.] It's not gonna be all right. I mean, it's like I say, 'Hey, man, I got a problem and I got to do this, man, uh, oh, it's over here. I did this here. I shouldn't have done that. Ah, let me go get me some drugs and alcohol. Let me go get some alcohol.' Okay. You, you violated two things. You've taken the money that you could maybe take care of this problem with over here, to buy some drugs to the point that you're just gonna get so high, you know what I'm saying, that you don't care no more, and make a greater problem. And when you come down, then you got a mushroom of a problem. [Mhm.] You know? See.*
> *Int: Instead of one, you've got ten.*
> *Charley: So, so it's being able to take control of your life and sayin', 'Hey, wait a minute. I don't have to get high to deal with the situation. Let me sit down and*

> *try to figure a way that I can go and talk to somebody and get some good advice, or make arrangements to take care of the situation.' And if I can't take care of it, then it ain't supposed to be taken care of. You know what I'm saying? See. Just move on to the next thing. 'Cause, like I'm always saying, you change the things that you can and those you can't change? Forget about them. Pass on. you know? And then you do that, you know what I'm saying; [you] don't stand there and cry over that spilled milk.*
>
> *Int: So you kind of accept your limitations.*
>
> *Charley: Right. 'Cause while you're sitting over there crying over that spilled milk, the whole milk truck might run over you.*

It is important to see here how Charley links "not caring" with creating a bigger problem. The nihilism against which we struggle in the modern world is created by and results in further distancing from others. This is why mutual exclusion cannot be the answer to our cultural dilemma. It is noteworthy that Charley's contrast case, in which the person shows up as having greater agency and self-discipline, is illustrated by the person seeking help from others, figuring "a way that I can go talk to somebody." The struggle for self-control is thus no longer the burden of the isolated, autonomous self: instead, it becomes the shared effort toward self-understanding. This recalls Benjamin's discussion of recognition by another as essential to agency:

> A person comes to feel that 'I am the doer who does, I am the author of my acts,' by being with another person who recognizes her acts, her feelings, her intentions, her existence, her independence. Recognition is the essential response, the constant companion of assertion...Recognition is, thus, reflexive; it includes not only the other's confirming response, but also how we find ourselves in that response. We recognize ourselves in the other (1988, p. 21).

Charley compares this process of developing agency and connection to athletic training:

> *Charley: And once you feel like you got control of yourself, you don't even—it's like, it's like a weight lifter. This is what I tell my classes. Like a weight lifter, okay? He wants to get his body all built up and everything. All right. What does he do? He constantly lifts weights. He constantly works out. So what do you have to do to become a non-smoker? Constantly work out telling yourself, I'm a*

> *non-smoker. I don't want to smoke. You got to keep telling yourself. Even when that urge comes on. Sit there, take 10 deep breaths. Do a breathing treatment. Take 10 deep breaths and tell yourself, I am a non-smoker. Pretty soon, your strength will be built up to where that urge come on to get a cigarette, unconsciously, you'll say, no, and keep on going. You won't let it go in that situation. But if you give in, here and there and there, you ain't never gonna be that body building champion...*
>
> *And, like I say, it's not a thing I be talking to people, that's something that I read in a book. It's about a thing I lived, you know. And so maybe this is why, sometimes, that when I let them know about these different feelings, and a lot them have experienced them, and know that I know what I'm talking about, you know. It's sort of like, well, man, hey. Well, come on, tell me a little more about how I can do--you know. [Mhm.] And this way, you know, then I'll be able to get them to try another little step, another little step, another little step, you know. And then as they go through that process of making those steps. They pretty soon find themselves not smoking at all. And, like I tell them now, that was the easy part. You know what I'm saying? The hardest part now, is not to go back.*
>
> *Because, you know, like I tell them this story too: I says, uh, I killed that little old man that was in my head who kept telling me, have a cigarette, Charley, have a cigarette. But I got a monsterman now. 'Hey,' as I walk past the refrigerator door, there's a guy screaming, 'Hey, Charley, some good old chocolate ice cream in here, come 'n get it!' (laughs)*

Discussion

Charley's transition was not the result of being forced to realize how his habits had excluded him from the human community and then resolving to change them; rather, it was the result of a persistent caring community that extended the invitation to be included. Such an invitation begins not from normative discourses of medical domination and social control, but from acceptance and encouragement that fails to be dissuaded by individual failures and resistances: in the private sphere, we call this a kind of unconditional love. Here resistance by the individual is understood not as an adversarial stance, but as a form of fear that interferes with trust. If this is understood, establishing trust takes precedence over other, more directive interventions. This requires patience and the kind of structural and institutional support that will allow caregivers to engage with patients, not merely process their bodies. It also requires a community of care that supports the caregiver.

Patience, as Borgmann (1992) has pointed out, has greater strength than power: "Patience has the time and strength to recognize complicated conditions and difficult people, to engage them in cooperation and conversation" (p. 124). It is patience that we must learn if we are to find a different way of being together, a way of being communities.

CHAPTER TEN

IMPLICATIONS FOR
PRACTICE, POLICY, EDUCATION, AND RESEARCH

The venture into the public realm seems clear to me. One exposes oneself to the light of the public, as a person. Although I am of the opinion that one must not appear and act in public self-consciously, still I know that in every action the person is expressed as in no other human activity. Speaking is also a form of action. That is one venture. The other is: we start something. We weave our strand into a network of relations. What comes of it we never know. We've all been taught to say: Lord forgive them, for they know not what they do. That is true of all action. Quite simply and concretely true, because one <u>*cannot*</u> *know. That is what is meant by a venture. And now I would say that this venture is only possible when there is trust in people. A trust--which is difficult to formulate but fundamental--in what is human in all people.*

Hannah Arendt (1994b, p. 22-23)

Introduction

This study assumes that human experience is relevant to public policy and public discourse about social problems. Readers accustomed to the abstract rationalism of most contemporary discussions of social and policy problems may find themselves impatient with the stories recounted herein. But this work suggests that it is a mistake to believe that these narrative accounts are immaterial to the problems which confront us as patients, as health care providers, as policymakers, and as persons. These voices from the margins speak powerfully on behalf of us all, since they point to the extremes of our common life. All of us need care, compassion, and community, and these cannot be reduced to abstractions nor to commodities without undergoing moral distortion.

The "problem" of heavy users of ED services, as this study shows, is not merely a local one, confined to the ED setting; it is many-branched, tenacious, and pervasive. Its explication provides an example of the way the personal, the public, and the political intersect around health care issues and, more specifically, around issues related to the body and its care--or its control. The body assumes importance because the body is so

central to the breakdown in our cultural project of understanding ourselves as independent, self-sufficient individuals. This is also why the study of "problems" in medical care provision, such as the one focused upon here, provides opportunities for insight into issues which affect everyone in our culture.

The themes identified here (legitimacy, heroism and helplessness, recognition, and community) are also reflected in policy conversations about wider social issues such as immigration, affirmative action, violence, assisted suicide, alienation, and the decline of citizenship. When we call into question the moral legitimacy of patients, it brings to the forefront questions about the moral legitimacy of our institutions of care; when others are dependent or helpless, it calls into question our own struggle to control our bodies, our lifeworld, and our systems; when we fail to recognize our patients as needful of care, we fail to be recognized as caregivers; when communities fail, we lose a sense of belonging, and our social covenant with one another is undermined.

The phenomenon of heavy ED services use calls attention to several interesting aspects of health care in the United States at the end of the twentieth century: a tension between the simultaneous processes of medicalization and demedicalization; a struggle for dominance between the biomedical and market models of health care; a widening cultural fear of dependency; and the difficulty in finding and preserving cultural spaces within which caring practices can be recognized, sustained, and extended.

Medicalization and Demedicalization[12]

"Medical" or "Social" Needs?

Throughout this study, I was struck by the simultaneous effects of medicalization and demedicalization on heavy users of emergency services. The definition of problems and needs as "social" or "medical" is critical to the way we understand ourselves. The fact

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[12] Fox (1994) lays out a more optimistic scenario of simultaneous medicalization and demedicalization than that articulated here.

that "medical" needs must be distinguished from "social" needs, and that there is such vigorous discourse about doing this, is evidence of how thoroughly "medical" problems are considered *individual* problems. Increasingly, however, even "social" needs are considered problems of the individual, as many of the participants in this study revealed.

As noted earlier, "frequent flyer" patients are often impelled to medicalize their problem: to transform their "social" needs (hunger, homelessness, social isolation) into "medical" needs (nausea, pain) because the "system" has no way to recognize the former in the absence of the latter. This situation can lead both providers and patients to "scam" or "game the system" (Morreim, 1991), provoking ethical conflicts and fraying the social contract between caregivers and patients and between both groups and health care institutions. The duplicitousness that the caregiving relationship takes on under such conditions is experienced as a constraining web (SmithBattle, 1995) that interferes with mutual recognition and closes down possibilities for action and change. Medicalization does at least indicate some effort to meet or mediate the ethical demand (Logstrup, 1971) involved in recognizing the suffering other (Levinas, 1989), in that it offers a limited inclusion in the human community, but because this inclusion is predicated on adapting to the language and definition of biomedicine, it is often an objectifying inclusion.

Demedicalization as Exclusion

The process of demedicalization, in contrast, is a process characterized by objectifying *exclusion*. Here the ethical demand represented by the presence of the other in need is denied, distorted, or refused. Several nurses noted disturbing changes in practice, such as providing less treatment for persons with chronic alcohol problems or discharging sick homeless people to the street; such practices deny recognition of common humanity and create ethical distress. What is not medicalized, as discussed elsewhere in this analysis, is criminalized. This process is experienced as abandonment by both patients and providers: patients feel rejected, helpless, and angry, and caregivers feel helpless and defensive.

What is reflected in these twin processes is abandonment of caregiving practices by the system that once supported such practices, amidst a fierce struggle for dominance between the biomedical and market models of medical care.

Biomedical and Market Models

Biomedical Assumptions

The biomedical model of medical care, as noted in the first chapter, assumes that individual characteristics, such as genetic predisposition, "lifestyle choices," and other factors are the chief determinants of "illness." Illness is assumed to be discrete from the rest of a person's life, a set of biological-physiological factors that can be separated from the effects they have on the person's social, class, gender, race, and employment status, and the effects these have on the body. It follows, then, that interventions primarily target the individual, and often even the specific body part or symptom; social factors are not seen as medical problems except insofar as they are "medicalized." This view also assumes that medical care is the chief factor in restoring or maintaining "health," a position robustly challenged by McKeown (1979), among others.

Market Assumptions

The market model of health care assumes that individuals are freely able to choose the best package of health care services; their ability to do so reflects their behavior in terms of their economic productivity. Those who earn more money are thus rewarded with more options as they "shop" for the best quality "product" in care. Quality is assumed to increase as institutions like hospitals compete for the consumer dollar. Physicians and other caregivers, likewise, are encouraged to "market" themselves to third-party payers as competitive providers by providing "cost-effective" care.

Models, of course, are not the same as practical understanding and practice, and both these descriptions are grossly oversimplified versions of theories that--within a limited context--have utility in describing some aspects of the medical treatment system. What both fail to account for is the health *care* system, a truism noted by many critics but one whose ramifications speak to the heart of our human condition and our cultural dilemma. Meanwhile, these inadequate models continue to exert powerful influences on our social institutions.

Individuals as the Problem.

In both these perspectives, heavy users of emergency services are themselves--as individuals--the problem. In the biomedical view, such persons are problematic because they do not comply with medical instructions to "take care of themselves" or go elsewhere for care and because their "social" problems bleed sloppily over into their "legitimate" medical problems. In the market view, heavy users of emergency services are a problem because they cannot themselves pay for the quantities of expensive services they seek and need; because legal mandates dictate that they cannot be turned away from the ED without an evaluation, and because their (socially undesirable) presence threatens institutions' efforts to attract more desirable "customers."

Conflicts Between Biomedical and Market Perspectives.

Heavy users of emergency services are emblematic of the current struggle between biomedical and market approaches to health care. As physicians' claims to authority in defining and delimiting the medical from the merely social have been challenged by increasing patient resistance to medical paternalism and by market forces which interpose third-party payers as monitors of physician activities, the biomedical mandate toward medicalization is countered by a market-enforced demedicalization. The problem of heavy alcohol use and its associated needs for assistance can be used to illustrate what I came to see as the simultaneous medicalization of certain "problems" and the demedicalization of certain groups of people.

Models of Alcohol Use.

Conrad and Schneider (1992) detail the historical development of alcohol addiction and alcoholism as disease concepts. They seat the commonly-held disease understanding of heavy drinking within the "therapeutic" (Rieff, 1987) contemporary self-understanding and within the political developments of the last fifty years, but they warn that the disease concept is still socially "contested." One of the newer challengers to the disease model of alcohol use comes from the market orientation in the form of the "rational addiction" model (Becker & Murphy, 1988). This model, based on economic theory, suggests that price increases may be effective in reducing alcohol consumption even among those who would be considered addicted to alcohol. Its assumptions include an implicit understanding of persons as rationally calculating their behavioral choices and free to make such choices independent of other aspects of their lives.

> Under the assumptions of the rational addiction model, consumers are rational in that they recognize the effects of current consumption on future preferences and incorporate this information in their current consumption decisions. The rational consumer of addictive goods recognizes that the cost of raising current consumption includes (in addition to the financial and health costs of the extra current consumption) all of the additional costs associated with the resulting increase in future consumption (National Institute on Alcohol Abuse and Alcoholism, 1993, p. 262).

This model, while still relatively untested, provides theoretical cover for the simultaneous medicalization of the alcohol "problem" and the demedicalization of poor *persons* who use alcohol heavily. Since poor alcoholics, on this view, are assumed to have made "rational" (if unwise) choices in their drinking habits and other life decisions, they and they alone are responsible for the consequences and for finding the resources to pay for treatment should they "choose" to seek it.

A third model of alcohol use could be broadly characterized as the public health view. Using the environment-host-resistance model, advocates of this persuasion argue that the social environment around alcohol should be the site of intervention (Mosher & Jernigan, 1988). The influence of this model is felt in campaigns aimed at controlling or restricting advertising of alcohol, increasing taxes, controlling availability and supply, and in research on the effectiveness of such intervention strategies (Scribner, MacKinnon, & Dwyer, 1994).

Economic Darwinism.

Stein (1990) suggests that the ideology of addiction serves a social-psychological purpose in that the stigmatized addicted persons serve as a repository for a "national malaise" and divert attention from deeper social problems. His intriguing argument is that the rise of a neopuritan "social Darwinism" is being reflected in changes in our medical care system:

> Only the physically and mentally and economically strong are worth bothering about. Others are permitted to languish or perish through neglect or are hastened out of sight and life by social policies that serve as externalized conscience. The recent proliferation of corporate, protocol-based hospital care (replacing more individual treatment with standardized care designed to get the patient quickly out of the hospital); of brief, short, focused, problem-oriented psychotherapies and family therapies; of technological, technique-oriented treatments that bypass relationship and meaning in illness and therapy--these are symptomatic of the minimalistic climate in which scapegoating and victimization become rationalized as normal (pp. 995-996).

Although Stein's psychologistic analysis leaves many unanswered questions, the findings of this study support his assertion that social Darwinism--supported by instrumental rationality-- is alive and well. The development of the rational addiction model provides theoretical justification for social policies which are often at cross purposes but which serve to reinforce the survival of the economically strongest.

Alcohol use was estimated to account for $99 billion in economic costs in 1990 (Institute for Health Policy [citing unpublished data from D. P. Rice], 1993, p. 16). Alcohol-related deaths were among the top ten causes of death for California residents in 1989 (Sutocky, Shultz, & Kizer, 1993). Yet policy messages about alcohol continue to be ambiguous and sometimes contradictory (Mosher & Jernigan, 1988). For example, tax subsidies for the alcohol industry coexist alongside excise taxes on alcohol itself. The effect of such policies is to shift the burden of costs to individuals and to the public and away from the private stakeholders in the national alcohol industry, which accounts for $92 billion in retail sales annually (Institute for Health Policy, 1993).

In this study, I puzzled over the question of whether alcoholism was currently being medicalized or demedicalized as I saw increasing reluctance to treat chronic alcoholic patients and resentment and hostility toward their presence in the ED. Resentment was also reflected in policy changes which would withdraw alcohol-related disability payments from persons who were unable to stop drinking within a specified time frame. Then I realized that alcoholism itself is still vigorously viable as a disease concept: it is the "street alcoholic" that is no longer welcome, because he or she has no ability to pay for treatment. Alcoholic persons with financial resources can avail themselves of the Betty Ford Clinic, private hospital inpatient programs, and other such elite services; those who have little or nothing, like the patients in this study, have far fewer options.

Detoxification services are often organized on social models which have no capacity to treat the medical complications of withdrawal in severely alcoholic patients, such as those in this study, who repeatedly were brought to the ED with seizures. Almost no inpatient medical detoxification services are available for those without insurance. For example, in the city and county of San Francisco, there were 11 programs offering inpatient hospital detoxification and rehabilitation services, but only one listed fees as "nominal," and this program limited eligibility to veterans. A very small detoxification unit recently opened at the county hospital, but eligibility is limited there to those with psychiatric co-morbidity. The other inpatient medical detoxification programs charge from $350 a day and up (Community Substance Abuse Services, 1995). Some outpatient medical detoxification programs are available, but this means that those patients who are homeless must leave each day and return to the streets, diminishing their chances for successful recovery.[13]

California's version of Medicaid also does not provide coverage for treatment services for alcoholic patients, with the exception of a few groups such as pregnant women, but it does provide coverage for emergency care such as revival from hypothermia, treatment of alcohol-related traumatic injuries, and fluid resuscitation in dehydration. This prejudice toward funding high technology "fixes" rather than effective treatment programs persists despite the fact that a large outcomes study from the state alcohol and drug agency found a one-third reduction in emergency room admissions and a 25 percent reduction in inpatient hospital days following treatment (Gerstein, Harwood, & Suter, 1994). Since this study clearly showed, as have others, that improvements in health and reduced utilization of services are found during and following treatment for substance abuse problems, and since the study also estimated that there is a $7 return (in reduced criminal activity, reduced use of medical treatment services, and other costs) for every dollar invested in treatment, it is apparent that neither the ideal of providing help to those in need nor the effort to contain costs is the underlying determinant of policymaking in this area. Instead, the cost control rhetoric has provided reinforcement for a dominant ideology under which private capital is supported and extended with public dollars, whether those dollars are the tax dollars expended in tax subsidies for the alcohol industry

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[13] It should be noted that the City and County of San Francisco has made an intense effort to coordinate treatment referral services as part of their participation in the Community Substance Abuse Target Cities Program. If some of the patients in this study were San Francisco residents, however, they nevertheless might be unable to find treatment appropriate to their circumstances, suggesting that in locales where such efforts have not been made, accessing treatment could be even more difficult.

or in providing technology-dependent services, or the personal dollars expended in alcohol consumption.

Singer (1986b) argues that a dual conception of alcoholism has emerged, in which it is both 1) a moral shortcoming and 2) a medical problem. I would argue, however, that the ascendancy of the market model has created a third dimension, namely 3) economic liability/opportunity, demarcated by the split between the *disease* of alcoholism and the *person* of the alcoholic that is determined along socioeconomic lines. This assertion is at least partially affirmed by the documented disparity between the need for alcohol services and the public financing and availability of such services.

For example, California ranks in the top ten states nationally on four measures of need for alcohol treatment: a population at high risk index; number of alcohol-related arrests; liver disease morbidity; and alcohol sales. Yet California ranks 39th in public alcohol treatment funding (Dayhoff, Pope, & Huber, 1994). Quite clearly, then, this means that while treatment is available for those with adequate funds (the disease is still recognized as such when it represents economic opportunity), it is not available for those without funds: people like those in my study who rely heavily on public or community hospital emergency services (and represent economic liability).

Such a split is compatible with the biomedical model's tendency to view disease as independent of the person in context; here, then, we see the two dominant and ostensibly competing models dovetailing to produce a situation in which recognition of medical legitimacy by caregivers must, in essence, be purchased. Mutual recognition of *personhood* is less and less available at any price. Human beings who fail to fit into the normative grid of efficient body processing and profitmaking fail also to be recognized as fully human (but those who do fit in often fail, as well).

The persons in this study who drank heavily and were considered to be alcoholics were poor; they were not seriously regarded as persons eligible for and warranting help.

This was evidenced by the absence of publicly-funded and situationally-appropriate treatment and care programs; the almost rote ED discharge instructions to "stop drinking," the absence of strategies to assist patients in staying relatively healthy *given* their known alcohol consumption, and the dismissive comments of staff about such patients. However, despite the fact that as many as 17% of injured ED patients test positive for alcohol (Cherpitel, 1989), medical and nursing staff are offered almost no teaching or training in dealing with persons who drink heavily (Martinez, 1990), and the temporal and resource contraints under which they work provide disincentives to seeking such information on behalf of their patients. Heavy users of emergency services, and emergency clinicians, are caught in the middle in the collision course (or, perhaps, the rapprochement) between the biomedical and market models. Unable to pay, regarded as useless for teaching material, and evoking social sanctions by resisting cure and control, "frequent flyers" enter a "no-care zone" (Estes, Swan, & Associates, 1993). Their repeated helpseeking is thus interpreted as "abuse" of a system that has abandoned the social commitment to care.

A Political Economy Perspective

Examining the problem of heavy users of emergency services from a political economy perspective enhances critical understanding. The political economy perspective focuses on studying and analyzing the

> interrelationships between the polity, economy, and society, or more specifically, the reciprocal influences among government...the economy, social classes, strata, and status groups. The central problem of the political economy perspective is the manner in which the economy and polity interact in a relationship of reciprocal causation affecting the distribution of social goods (Walton, 1979 [cited in Estes, Swan, and Gerard, 1984, p. 28]).

This perspective emphasizes the social and economic conditions that create, reflect, and reinforce the taken-for-granted "reality," including the common assumptions about the status of certain groups or classes of people within the society. In this perspective, the individual is not the focus of analysis; rather, the emphasis is on the structures which

support prevailing conditions. Questions focus on who is served by maintaining social arrangements as they are and how those negatively affected accept the social controls. Class, race, and gender issues are foundational.

Most of the heavy users of emergency services who participated in this study, as noted previously, had one or more chronic medical conditions; most of them were poor, and many were homeless and/or socially isolated. A massive body of research documents that the poor have higher morbidity and mortality from almost every cause than those of higher socioeconomic classes (Dutton, 1986; Haan, Kaplan, & Syme, 1989; Kaplan, Haan, Syme, Minkler, & Winkleby, 1987; Marmot, Rose, Shipley, & Hamilton, 1978; Marmot, et al., 1994; Nelson, 1994; Susser, Watson, & Hopper, 1985; Syme & Berkman, 1994; U. S. Department of Health & Human Services, 1990). The homeless are especially at risk, particularly those who use alcohol heavily (Centers for Disease Control, 1991; Fisher, Shapiro, Breakey, Anthony, & Kramer, 1986; Hibbs, et al., 1994; Wlodarczyk & Prentice, 1988). Poverty is itself a major risk factor for disease and disability, as is social isolation (Berkman, & Syme, 1979; House, Landis, & Umberson, 1988). Yet poverty and social isolation, like alcohol use, are largely viewed as individual problems, the result of not working as hard as others, not trying hard enough, not being as careful with what one earns, or other aspects of "bad judgement."

Continuing to view both chronic illness and/or dependency and poverty as problems of individuals rather than problems of society serves several functions in maintaining the status quo. It enables those in positions of power and control to distance themselves from responsibility for the care of the poor and sick, since the poor and sick are viewed as being at least partly culpable. It diverts attention from economic policies that favor the wealthy as a group and disadvantage the poor, such as regressive tax policies and disinvestment in the public sector (Whiteis & Salmon, 1994). Finally, it helps maintain a vast industry of well-paid "helpers" whose learning of technical skills is practiced and demonstrated on the bodies of the poor in the public teaching institutions that are often their only source of care.

Estes (1984) has drawn attention to the way the poor are further segmented from mainstream society by their relative "deservingness" of aid. Those who are generally considered the "deserving" poor (often, the middle classes) are differentiated from the "undeserving" poor by their class status and productivity. The stigmatization that is associated with heavy users of emergency services means that they tend to be viewed as more or less "undeserving," like their long-ago almshouse counterparts (Friedman, 1994; Rothman, 1993), and the present distribution of health care resources is reflective of and helps to maintain this distinction.

For example, the coverage of high-technology procedures by most public health insurance arrangements, which is presumed to be morally neutral, benefits the technology industries and their shareholders as well as the institutions and providers who use them both as therapies and as drawing cards to attract "good customers." Academic medical centers emphasize high-technology research in maintaining status and obtaining grant funding (Rettig, 1994), and are increasingly linked with technology industries through formalized economic relationships (Atkinson, 1994; Blumenthal, 1994).

Though the poor may benefit from some of these services, the need for their use might often be averted by basic, low-technology care, social intervention, or income, food, and housing support, little of which is covered by public insurance. Such "ordinary" measures do not reap "extraordinary" profits for investors (McKenzie, 1994), including entrepreneurial physicians who have financial stakes in drug companies whose drugs they prescribe or technology services to which they refer their patients. They do not require nor support the vast "medical-industrial complex" (Relman, 1990, 1994).

Rather than framing the "problem" of heavy use of emergency services as the need for adequate low-technology care and basic public services, then, it is viewed as one of resistance to medical compliance, "abuse" of public trust, and individual moral failure, as Chapter Six revealed. The rhetoric of defederalization and "local control," predicated on the so-called popular disenchantment with government (Navarro, 1990, 1994) camouflages a trend toward demonization of the poor and dependent in public discourse ("Compassion for the Poor," 1994). This trend is reflected in the vocal political resentment and anger toward "welfare mothers," immigrants, homeless persons, ethnic minorities, and others in lower status, unorganized groups who have little ability to defend themselves, and the increasingly restrictive laws and regulations designed to control them. Heavy users of emergency services are such a group. Rendering such persons more "other" and more problematic in turn diverts public attention from the shrinking sphere of public security and care and mobilizes support for further "cost controls," the practical effect of which is to increase deprivation and increase private profit.[14]

The poor are relatively powerless in a society in which participation is based on one's ability to purchase. Still, their sheer numbers could make them a potentially powerful group were they organized and verbal. In the health care arena, however, the lack of uniform health care entitlement programs means that even if groups of poor persons tried to organize effective protest, the size of their groups would be limited. There is no single federal program providing medical or health care services for the poorest; rather, there are fifty different state Medicaid programs, with widely varying eligibility requirements, funding, and coverage (Kaiser Commission on the Future of Medicaid, 1995). The patchwork of state Medicaid programs, which one report described as providing "poor health care for poor Americans," must meet certain federal requirements, but because states have great leeway in funding and defining those programs, even the "mandatory" coverages are not always consistently provided (Erdman

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[14] Himmelstein & Woolhandler (1995) found that among US residents, Medicaid recipients and the uninsured both had similar measures of access, and access was commonly restricted, even for those with private insurance, by the burden of costs for which individuals were responsible.

& Wolfe, 1987; Grogan, 1992). Patients on one side of a state line will be provided with lifesaving or preventive care and patients on the other side of that line will not.

States, in turn, have shifted more of the economic burden of caring for the poorest people to counties, which in turn provide varying resources for their poorest residents. In California, for example, medically indigent eligibles for the state Medicaid program, Medi-Cal, decreased by 60% from 1981 to 1990 after statutory changes which eliminated eligibility for many people. Those without any insurance coverage are thus now the responsibility of the counties in which they reside (California's Medical Assistance Program, 1991). Such patients are at higher risk for negligent and substandard medical care (Burstin, Lipsitz, & Brennan, 1992), a risk which may be heightened rather than reduced by the competitive pressures now faced by public hospitals.

One of the practical effects of such policy changes has been to increase the burden on public hospitals, particularly those in urban areas, at a time when they face increasing competitive pressures from private facilities (McKenzie & Bilofsky, 1994). The actual economic effects are much harder to sort out, given the inventive revenue-transfer schemes between states, counties, and the federal government (Coughlin, Ku, Holahan, Heslam, & Winterbottom, 1994; Levit, et al., 1994). There is little doubt, however, that the load of public hospitals has increased; one study conducted in California suggests that private hospitals' response to competitive pressures and prospective payment system effects has been to reduce their provision of "uncompensated care" (care provided to the poor and uninsured) by at least 36%, prompting warnings about the potentially jeopardized "safety net" (Mann, Melnick, Bamezai, & Zwanziger, 1995).

Further fragmentation is seen in the way each disease entity or policy problem is viewed as more or less discrete from the others.

> Rather than confront the general problem of meeting basic human needs, including health care, on an equitable basis, American politics has tended to fragment the issues, leaving each subgroup (the aged, the handicapped, victims of AIDS or

> kidney failure, etc.) to struggle for its own special entitlements and programs, in a political environment increasingly dominated by the ideal of market competition (Annas, Law, Rosenblatt, & Wing, 1990, p. 36).

This constant competition for resources which, we are continually reminded, are limited, keeps these subgroups warring with one another over their piece of the pie, rather than acting together to envision and demand fundamental changes in the system itself.

Whether they are well or poorly funded, however, and whether they are administered by federal or by local authorities, Medicaid programs and other insurance schemes support and reinforce both the market and biomedical models of health care by perpetuating the notion that health and illness are individual conditions which should be addressed by judiciously utilizing medical-scientific knowledge to "fix" individual pathophysiologic states.

Who benefits from seeing heavy ED users as illegitimate, as a problem population whose needs are not deserving of being met by medical care institutions? To the extent that such patients are uninsured or covered under capitated arrangements, hospitals benefit when providers expend fewer resources on patients whose care may be largely or at least partially uncompensated. Insurers under fee-for-service, and their shareholders, also benefit, because they minimize expenditures on an otherwise high-cost group of patients. Third-party payers offer physicians and other providers economic incentives to keep costs low, making minimal treatment of high-cost "undesirables" financially palatable. The conscious or unconscious strategy of neglecting low-technology needs means that more resources can be expended on more profitable high-technology treatments. Medical residency programs seek to offer their students experience in trauma and critical care; in some perverse respects, it may actually be counterproductive of learning to help heavy ED users with low-technology needs, thereby potentially averting their need for more acute services and the learning opportunities afforded thereby.

This analysis is by no means comprehensive, but it serves to illustrate the advantages of the political economy perspective in critically examining taken-for-granted understandings about this stigmatized group of persons. Its great advantage is that it does not shirk examination of how issues and problems come to be defined as such. Political economy asks questions about who benefits, who loses, and how they are different.

Because the political economy perspective is grounded in an ethic of justice, its analyses tend to focus on questions of difference: differences in distribution of resources among groups of persons, based on differences in class, race, or gender; differences in power and status; differences in ideology. In this study, issues of class have obvious relevance, because so many of the "problem" patients are poor. These differences are of critical importance in understanding social problems and helping us look beyond the "obvious" in our conversations about social problems. But we also need to look beyond the "obvious" in relation to our commonality.

Benner (1995) calls attention to what she calls the "middle terms": those areas of common human experience which stand between ideology and physiology. It is in this often-silent area that we find practices of recognition and relationship; it is here that we find embodiment, and it is here--and, I would argue, *only* here--that the possibility of finding a way out of our cultural stance of control and domination appears.

Cultural Fear of Dependency

The Terror of Dependency

The social creation of dependency, and the cultural terror it evokes, are not merely political problems; they are existential ones. We are every one embodied, finite, and needful of others; our existence is not merely made more pleasant or endurable by the presence of others, but is constituted by it. This mutually interdependent aspect of our common life was once more apparent in our social institutions; we depended upon one another directly to help with harvest, construction of shelter, care of the sick and infirm, giving birth, and dying. Community structures encouraged and supported our interaction with others in cooperative ways.

The contemporary medical treatment system, in which care has been removed from the sphere of public participation to a zone of professional dominance and control, has transformed our common embodied vulnerability into "private troubles" (Mills, 1959) that we pay others to keep controlled and socially hidden when we cannot manage to hide them alone. The rise of professional dominance (Starr, 1982), the hegemony of a "science" based on notions of value-free objectivity, and the linked assumption that the free market is the best way to address the distribution of public goods have contributed significantly to the reduction of meaningful public life to mere commodity exchange (Frankford, 1994). Economics has become more than one among a number of tools we use to organize our lives. It has become the dominant metaphor by which we understand ourselves. Tellingly, as Starr (1982) notes in his massive treatise on the American medical system, "there are no relations of dependency in the ideal market" (p. 23).

Our interdependency, however, is the opening through which we may meet the other. The great danger in denying and fearing dependence, in converting it to a private and individual problem (or even a problem of affected classes), is that we may become the kind of beings who can no longer recognize one another as vulnerable, that we may become incapable of trust. This is reflected in the gnawing fear that keeps us behind locked doors and barred windows, suspicious of those of different ethnicities and classes, inclined, in the absence of dialogue, to violence.

I recently noticed a graffito on a wall not far from where I live. Beneath a sketch of an obviously fiercely angry boy, his brows a black "V" in the intensity of his self-assertion, the artist had written, "*I don't need no fckn lullaby* [sic]." This is the street-level version and result of the primacy of the self of possession, the disengaged, utterly autonomous illusion of ourselves that we cultivate to fend off dreaded dependency. This self-understanding crosses all classes; it is as easily the aggressive businessman (or the rational policymaker) as the ghetto kid who scrawls this message of apparent liberation. It has great appeal in a culture whose heroes are those who pull themselves up by their own bootstraps, the cowboys, the solitary explorers of new territories. But it cannot be sustained. We all need lullabies; we long to be comforted when we are hurt; we need a safe place in which to sleep. The yearning to be heard by others, to be part of a human community, is embedded in the drawing of that angry, defensive boy as surely as it is in the written (and thus implicitly shared) anxieties of Descartes' *cogito*. It is also embedded in the stories in this study.

Difficulty in Finding Public Space for Care

As our social institutions standardize and routinize care into a set of procedures, as our "creature comforts" are presumed to be addressed only by individual effortful striving, as we lose the language within which we can talk about nonquantifiable goods like love and kindness, we risk living in a "culture of contacts" in which, as Rieff (1987) suggested,

> men may no longer need to have something in common, as an end, to love. The organization of indifference may well succeed the organization of love (p. 239).

Human Beings as Standing-Reserve

Heidegger (1977) warned that the totalizing character of modernity, in which the human projects of care and relationship are subsumed by the system's continual striving toward increased efficiency and optimal ordering for its own sake, threatens to turn human beings themselves into mere standing-reserve. As this occurs, human beings themselves become a mere resource to be used; in this context, care and concern for others lose their meaningfulness (Dreyfus, 1993). The struggle, in this study, by both nurses and patients to find ways to make caring make sense in a market-dominated environment reveals pockets of marginal resistance to this totalizing tendency.

The words we use to talk about ourselves have power (Levine, 1989b). Words not only name, but are constitutive of who we are. When we regard ourselves as "consumers," as we so commonly do nowadays, we leave out our ability to give, our attunement with others on terms other than those of commodity exchange or power discourse. Comfort when we are hurting, for example, cannot be purchased, nor can it be socially engineered, but it can be encouraged and spoken about as something worthy of our public concern. Why should comfort and care be confined to the private sphere (Tronto, 1993)? Why should we feel, as we do, faintly embarrassed to talk about such things in terms of public policy?

As the stories in this study reveal, the private sphere cannot support caring practices in the absence of public and social supports for such practices. To be a "consumer" not only requires too little of us: the "consumer" is literally devouring the space of our public life and leaving us abandoned, "unencumbered selves" (Borgmann, 1992, p. 3) who bitterly pretend we can live without lullabies.

The terror of dependency, then, points to the need for a different kind of policy analysis: one that begins with a fundamental reconsideration of what it means to be a human being. Borgmann argues that

> The dominant discourse about the future of our society is composed of the vocables of prognoses, projections, extrapolations, scenarios, models, programs, stimulations, and incentives. It is as though we had taken ourselves out of reality and had left only objectified and disavowed versions of ourselves in the universe we are trying to understand and shape. We vacate our first-person place and presence in the world just when we mean to take responsibility for its destiny. Surely there is deprivation and helplessness in this (1994, pp. 2-3).

The way to overcome that helplessness, however, is not through further attempts to control, rationalize, abstract, generalize, standardize, and dominate: it is through attempts to name and understand our common humanity. Vaclav Havel (1990) has called for such a transformation of politics, an abandonment of efforts to achieve universal systemic solutions through technocratic, utilitarian means in favor of a rehabilitation of practices of human understanding that aspire to more humble, limited ends. Kelman (1992) makes a similar kind of plea for concern and care in urging that we work to develop "cooperationist" institutions rather than adversarial ones for resolving conflicts over public policy.

Nussbaum (1993) points out that the contemporary cultural image for the human agent is that of the hunter: active, controlling, impenetrable, and solitary. Perhaps, she suggests, an image of the human agent as rooted plant, both active and receptive, trusting in the world and in others, connected with others, might better serve us now. Such an image calls forth

> A kind of human worth that is inseparable from vulnerability, an excellence that is in its nature other-related and social, a rationality whose nature it is *not* to attempt to seize, hold, trap, and control, in whose values openness, receptivity, and wonder play an important part (p. 20).

The Essential Dimension: Care

In the first chapter, I sketched three dimensions that seemed predominant in constructions of the "problem" of heavy users of emergency services: responsibility, efficiency, and justice. The findings of this study suggest the existence of another and more fundamental dimension: the dimension of *care*. As Benner (1994b) and others (Bellah, 1994) have pointed out, this dimension has been rendered almost invisible within our social institutions, although they could not exist without care. Because caring is generally regarded as an individual sentiment, rather than the primary way we take up being human (Benner & Wrubel, 1989), it is neglected or trivialized in our public discourse.

Like the other dimensions, care could perhaps be characterized as a continuum, ranging from anomie, nihilism, and social alienation at one extreme to engaged community on the other.[15] Here I specifically do *not* mean to suggest a particular normative notion of community, but I do want to contrast the meaninglessness of not caring, within which nothing stands out as worthy of our commitment, with the kind of engagement in meaningful projects with the aim of the common good that seems to characterize community: something like what Kelman calls "public spirit" (1992, p. 178).[16] The narratives of the persons who participated in this research help to make the care dimension visible and call attention to the way care is distinguished from control and irreducible to justice, necessary though that perspective is in a society as adversarial as our own.

Benner and Wrubel (1989) draw attention to several ways that caring is primary. First, caring creates possibility. Caring means that certain things matter more than other things, and thus stand out as worthy of doing; caring thus motivates and inspires our actions. Recall Charley's (Chapter Nine) discussion of how, when he was drinking and using drugs, he didn't care "if the next person lived or died," and how he contrasts this with his life now, which is characterized by--and fostered by--concernful involvements with others. Caring is not mere sentiment; it is constitutive of being fully human. As in the story of the nurses who could no longer see Alice as anything but a "ghoul," partly because she no longer seemed to care about anything, even herself, and partly because others could no longer find a way to care about her: when caring is lost, something essential to our humanity is lost.

Second, caring enables this connection with and concern for others, and in this way helps us make distinctions and better discern what is needed in particular situations. Benner and Wrubel point out that

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[15] This conceptualization does not allow for the phenomenon popularly identified as "caring too much" or "loving too much" because caring is here not understood as a private attitude of an individual.

[16] Kelman regards self-interest as the opposite of "public spirit." I would argue, however, that if we accept the notion that persons are in some very essential ways constituted by their connections with others, a radical form of self-interest is the existential equivalent of alienation and nihilism.

> parenting "techniques" do not work unless a basic level of attachment and caring exists. In fact, parenting techniques are not even useful or possible unless the parent is already engaged in the parenting situation through caring. But for those already involved in caring for and about particular children with particular concerns, some techniques will show up as more desirable and workable than others (1989, p. 4).

This is why caring for patients cannot be reduced to a set of tasks or procedures, and why it is critical that public policy support social and institutional arrangements that make public care not only possible, but encouraged.

Finally, caring sets up conditions of trust that allow for the possibility of giving help and receiving help (Benner & Wrubel, 1989). As the narratives of this study reveal, issues of trust between care providers and patients are central to the construction of the problem of heavy users of ED services. Patients who mistrust their caregivers may engage in "scams" to try to get needs met; providers who mistrust their patients distance themselves and may miss critical cues to the "real" problems underlying a particular patient's visits (Scott, Aiken, Mechanic, & Moravcsik, 1995). Temporal and structural constraints in the ED setting are barriers to developing relationships of trust, as is the lack of adequate referral resources for the kinds of low-technology care needed by many ED patients. Issues of trust also lie at the heart of many market-oriented reforms, which assume that individual or institutional self-interest, rather than the common good, is (and possibly should be) the prime motivator for human actions within the health care system, and thus emphasize controlling providers, hospitals, and patients over providing care (Stevens, 1989). The result is systemic adversarialism.

Current changes in the health care system threaten to remove *care* and leave only *system*, to the detriment of our collective health as a society. The market perspective dominates all others and, I would argue, is heavily weighted toward the extreme of alienation and nihilism. Care is reduced to "consumer satisfaction." Since the market orientation encourages the quantification of medicine in order to assure profits and control costs, aspects such as care which are fundamentally resistant to quantification become dangerously marginalized.

Implications for Practice, Education, Policy, and Research

Implications for Practice

Engaged ED clinicians have no doubt already grasped many of the implications of this work for the practice setting. The ability to sustain a caring vision and a dialogue about what constitutes good practice depends upon our ability to preserve the cultural and institutional space in which each of these can exist. This means that nurses and physicians must consciously and actively resist being lured into taking up the language of market rationality, because its primacy renders impotent our already too-sparse public language for practices of care and commitment. For nurses in particular, whose practice is constituted by care, whose clinical knowing and satisfaction in work derives from interaction with patients as much as from "cure"-oriented activities (Anspach, 1987), protection of language is a clinical and moral imperative.

Without language, public caring practices wither. Protection and sustenance of caring practices begins with preserving and extending our language of care and connection and resisting totalizing language that collapses meaningful distinctions between persons. For example, we can refuse to call our patients "consumers" or "customers." "Consumer satisfaction" is simply not the same as feeling cared for, and as clinicians we must not only understand this, but articulate it on behalf of ourselves and those for whom we care.

Waitzkin and Britt (1989) suggest that clinicians can shift the focus of medical discourse by noticing how the "social" aspects of illness are marginalized and trying to address these. Theirs is a laudable effort to call attention to how the ways in which we talk can serve to maintain distance and dominance, and, further, the way structural and social factors affect our definitions of illness and related problems.[17] The present study suggests that clinicians strive for the humbler yet perhaps more difficult goal of simply recognizing the patient as a person. This effort involves attentiveness, humility, and risk, since it involves our attempt to be recognized as well as our attempts to recognize others. Normative, deficit-identifying approaches to patients exclude the kind of advocacy (Curtin, 1979; Gadow, 1989) patients seek when they come to the ED looking for global "help." What Lazarus (1985) called "the trivialization of distress" can result when providers understand patients solely in terms of problems to be fixed.

As clinicians, this kind of recognition and advocacy means surrendering illusions of our omnipotent abilities to "fix" things. It suggests an attitude of openness: of listening, witnessing, and waiting rather than leaping in to take control. This may sound like a tough call for ED clinicians, who are primed to leap in and fend off death, and this is not meant to suggest that clinicians should stand back at a distance and watch passively. It is, however, meant to challenge the instrumental stance we often assume toward patients, in which they become standing-reserve for our needs or the needs of the system rather than being seen as fully human.

What would this kind of recognition look like in practice? This study suggests many examples. In patients who use alcohol heavily and chronically, for instance, the normalizing discourse of control suggests that the goal of care should be to help the patient stop drinking. A practice that affirms caring and connection, rather than seeking control, could include teaching that begins from a position of openness to possibility and accepts the patient as a person who drinks, rather than beginning from the normative assumption that the patient must abstain. This is a variant of "following the patient's lead" (Benner, 1994c). A response-based practice recognizes that helping is always a contingent process (Benner, Tanner, & Chesla, in press; Hooper, in progress). Such a

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[17] Also see Padgett & Johnson (1990).

practice may allow the underlying meanings of the patient's visits to the ED to emerge. For example, Buddy's visits were a chance to rest; Matthew's were opportunities for nurturance and comfort; Mike's were a way to maintain a transitional identity and safety. As Charley's narrative revealed, change is not always accomplished by applying the correct and efficient solution to the problem. Sometimes only time, trust, and tiny incremental movements toward possibility can make a difference. But the difference, understood cumulatively, can be profound.

The patients in my study whose everyday lives were organized around their drinking clearly were concerned about taking care of themselves, despite their alcohol habits. To note one example, their many stories about the importance of eating (Malone, in progress [2]) suggest that teaching aimed at addressing the increased nutritional needs of those who drink heavily might be welcomed. Practical suggestions about available, affordable foods that might help patients avert or minimize nutritional deficiencies could be made part of discharge teaching, offered in a nonjudgemental manner.

This approach contrasts with the assumption in most clinical and policy literature that the way to deal with nutritional problems in chronic alcoholic patients is to urge abstinence, or, that effort failing, to admit the patient for technological interventions (intravenous fluids, nutritional support) when his/her nutritional status deteriorates. Accepting the patient "as is" opens the possibility for meaningful dialogue which may potentially include encouragement to stop drinking but is not limited to such admonishments.[18]

This is not to suggest that caregivers simply teach patients to better adapt to oppressive social circumstances or physiologically destructive habits. It is, however, to suggest that, especially with socially marginalized patients such as many of those profiled

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[18] Hall (1994) suggests that individual problematizing of alcohol use and development of strategies for change depend on validation from others and are made more difficult by stigmatization and other social, political, and economic factors not easily modified by individual actions.

here, efforts toward emancipatory consciousness begin with small movements toward inclusion, understanding, and acceptance. Trust is a prerequisite to empowerment, particularly for those whose daily survival is based on a stance of extreme caution in relation to others.

Discharge instructions from the ED could be made patient-relevant, not merely disease-relevant. The medical records review conducted for this study revealed that too often, such instructions are given as a kind of medicolegal formality, not as realistic expectations given the patients' actual life situation. For example, Sam's instructions for wet-to-dry dressing changes were unworkable for a person living on the street. Yet for providers to engage with patients enough to understand what will be relevant to them, institutions must provide incentives that encourage patience rather than urgency (Scott, Aiken, Mechanic, & Moravcsik, 1995).

ED and community providers could organize institutionalized, innovative practice links between the ED and community settings. For example, the findings of this study suggest that having a group of visiting nurses or community health nurses whose base of practice was the public hospital ED might offer possibilities for coordinating non-medical and medical services in a more compassionate way. This kind of linkage would also offer possibilities for early identification of system problems or worrisome trends, since the ED setting often is the first place such problems appear when systemic or local changes have been made.

Providers can also utilize their organizational capability to identify and challenge institutional impediments to good practice, such as staffing patterns that assume practice to be a series of tasks, assignable in assembly-line fashion, that are performed on the objectified body of the patient-"consumer." Although this is difficult, especially for nurses, who have too often made adaptation a hallmark of their profession, the practice of nursing also embodies older traditions of activism. Nursing's marginalized traditions of social welfare activism and political advocacy, as exemplified by the settlement-house movement of the early part of the century (Estabrooks, 1995), may be moral sources for contemporary nurses. Lavinia Lloyd Dock, the fiery foremother of contemporary nurse activists, called for nursing to "consciously make itself a moral force on all the great social questions of the day" (quoted in Estabrooks, 1995, p. 157); such a call has perhaps never been more urgent than it is today (Moccia, 1990).

Implications for Education

This study affirms that the effort toward critical scholarship in nursing education (Thompson, 1987, 1990) is essential in preserving nursing practice, since the totalizing aspects of our systems, and their increasing intolerance for and inability to accomodate human embodiment (as distinguished from body processing), human concerns (as distinguished from biomedical or economic concerns), and human *beings* (as distinguished from "consumers") constitute grave threats to authentic practices of care. However, the critical perspective, which has been characterized as a freedom *from* dialogue linked with an ethic of rights and justice (the justice dimension), must be complemented by a freedom *to* dialogue about the substantive goods embedded in public caring practices (the care dimension) (Benner, 1990; Taylor, 1994b). Recognizing excellence in practice as itself a source of clinical knowledge and growth is a radical notion, the pedagogic implications of which we have yet to explore in depth.

Freire's (1990) emphasis on problematization as a learning strategy, as contrasted with problem-solving, offers promise for this type of educational effort, as does the use of clinical exemplars (Benner, 1984) to illustrate the qualitative distinctions and nonformalizable, contingent reasoning that nurses use in caring for patients. Use of exemplars is particularly promising because it holds out the possibility of teaching practitioners to be more aware of how reflection-in-action (Schon, 1988) can extend their clinical grasp. However, such aspects of learning can never be made fully explicit;

attempts to formulate lists and rules for practice inevitably reduce and can render meaningless the very distinctions so critical to skilled practice. This is why "critical pathways" and prognostic scoring systems can never replace the qualitative distinctions made by practitioners in particular situations with particular patients.

Educational institutions must also be innovative in developing new models for practice. The constriction of the hospital setting does not mean that people and communities no longer need care. Nurse-run clinics or safehouses might better meet the needs of ED patients whose primary reasons for utilizing the ED are nonmedical, yet who have genuine needs for health services.

In addition, it is essential that the educational preparation of future clinicians include an awareness of how the profession has historically positioned itself on the social issues of the day. Coursework in history, policy, and ethics is not mere icing on the cake of "real" knowledge about anatomy, physiology, and psychology; it is essential to excellence in practice. Such study situates the student within the ongoing ethical conversations of the profession and grounds the novice practitioner within the traditions of public caring practices. It also helps nurses develop and enlarge upon the language they need if they are to protect and defend caring practices in climates dominated by biomedical and market models. Such an emphasis is also needed in educational programs in medicine, law, public health and public policy.

Implications for Policy

Policy decisions are fundamentally *moral* decisions. Despite the dominance of rational-technical language in policy discourse, policy choices are ultimately made on the basis of social values that are often implicit and unstated. The choices of what issues to study from a policy perspective, the ways questions are framed and answers analyzed, the way decisions are implemented and the discourse within which policy questions are situated all reflect understandings of what is, what is possible, and what is good, whether or not these are articulated (Estes, 1979, 1991b). Unfortunately as Levins and Lewontin (1985) point out, "after questions of fact are formally freed from questions of value, they are not easily rejoined" (p. 207). The stories of people like the participants in this study draw attention to the moral aspects of policy and challenge the notion that policy and practice decisions are based on rational calculation and scientific "fact." Instead, they suggest, our policy and practice are often based on unquestioned, taken-for-granted understandings (Weiss & Bucuvalas, 1980).

"On the surface," observes Rothman (1990),

> a term like "surplus bed" seems to be value-free, an indicator of utilization of space that is neutral in measurement. But, in fact, the term is value-laden, reflecting very particular and contemporary assumptions about where and how health care should be delivered (p. 159).

It is vital that policymakers and planners who are making choices for us all do not displace their "personal," human concerns about care with their abstract, "depersonalized" concerns for efficiency and economy. For example, the assumptions underlying market models of medical care, as discussed above, include the rational, fully autonomous individual who is free to make choices from a selection of options. Such a conception of agency and personhood not only fails miserably to account for patients like those profiled herein; it also fails to account for the rest of us, who do not always make decisions based on what is "rational," are not always able to keep up the illusion of independence and autonomy, and do not always experience ourselves as having choices to make.

Yet much of our public policy is set up along the lines of contractual models, in which all parties meet as equals in a free market. Managed care policies, for instance, that assume primary care linkages and economic disincentives will decrease ED use, are misguided when applied to a population of homeless persons. Not only do such policies reflect a basic intent to control costs, rather than to provide good care, often with disastrous results (Soumerai, McLaughlin, Ross-Degnan, Casteris, & Bollini, 1994), but they fail to address the primary needs of such persons, which are often essentially non-medical in nature. Our disgust with the emerging role of social victim (Delbanco & Delbanco, 1995) calls attention not only to the waning of an ethic of personal responsibility, but of genuine social responsibility as well, since these two, it seems, are inextricably, ineffably intertwined.

Our policy discourse needs to shift from the concern with social engineering to the concern with the substantive good. For example, this study might, on the surface, suggest the need for "better," safer homeless shelters. Perhaps, instead, we need to consider the larger questions of what it means to tolerate homelessness, what it says about our "values" that we affirm the individual "right" to be in despair. People who have no place in which to live need incomes and real homes, not better homeless shelters and temporary hotel rooms with no hot water. Our primary concern must shift from protecting the negative freedom from interference, which itself too often represents an abnegation of public concern, to providing for a positive freedom to do, to be, to belong. It must shift from providing for a healthy *system* to providing for healthy--and necessarily diverse--*communities*.

This shift in focus, however, must be accompanied by a shift in actions. We have become inured to the sterile and ostensibly value-neutral language of scientific-economic rationality in working out policy accommodation between various interests. This rhetoric, like the ominous "language conventions" with which Nazi leaders spoke comfortably of mass murder in entirely rational everyday conversations (Arendt, 1992), leads us to believe that policy decisions can, after all, be made in the absence of wrestling with the messy moral questions they are the attempts to answer. This tendency to avoid overt moral-political conflict by substituting the rhetoric of science is peculiarly American, as Grogan (1992) has pointed out in relation to health care. It has not served us well. Too often, as Vladeck (1990) has argued, "rhetoric...has come to substitute for policy" (p. 313).

In our commodified age, even our rhetoric has been reduced to catchy advertising slogans and "sound bites." By such means genuine conflict is not resolved, but trivialized and covered over. Perhaps if we more overtly argued out our moral questions, to some degree of depth, on the national stage, we would have less need to assert our differentness in forms of violence. Perhaps we might even revitalize the role of the concerned citizen, now subsumed under the vacuous opaque mantle of "consumer."

One pressing policy question raised by this work is when we begin to save a life, and what it means to do so: to put it another way, what are we saving the life *for*? [19] The participants in this study point to this question by uncovering the urgent needs for basic sustenance and care experienced by many members of our society. Twenty-three percent of patients in a New York City municipal hospital survey experienced hunger (Rosenberg & Bernabo, 1992). From seventeen to as many as forty-one percent of those depending on soup kitchens in urban areas are homeless (Bowering, Clancy, & Poppendieck, 1991; Rauschenbach, Frongillo, Thompson, Andersen, & Spicer, 1990). Homeless people are more likely to have inadequate meals and poor nutrition than housed people (Wiecha, Dwyer, & Dunn-Strohecker, 1991). Almost 15% of the people in our country--36.9 million people--were below the poverty level in 1992, which for a family of four meant an income of less than $14, 335 (U. S. Bureau of the Census, 1994). As Kleinman (1986) pointed out almost ten years ago,

> There is no longer any doubt that the major gains in the health of communities are primarily the result of macrosocial changes which yield three types of improvements: in nutrition, housing, family economics, water supply, sewage disposal, and education; in great inequalities in the distribution of resources within

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[19] Anspach's (1993) study of life-and-death decisionmaking in intensive-care nurseries raises similar questions. She points out that "both the bioethical and the public discourse on neonatal intensive care treat decisions in the nursery as though they are unaffected by social forces outside the nursery. In fact, the political economy and the epidemiology of neonatal intensive care not only raise macrosocial issues of policy but also create a set of social, ethical, and practical dilemmas for those who make life-and-death decisions" (p. 174). She points to the paradox involved in saving lives using high-technology methods while withdrawing resources from social services and public health.

> populations and relative deprivation across groups and statuses (gender, class, caste, age group, and so forth); and in provision of and access to public health and health care programs. Health status is a function of those aspects of social development. We do not require a single additional study to be able to say with confidence that where social conditions are altered, so as to remedy these interconnected problems, health improves (p. 181).

Yet we continue to conceptualize our policy options only in terms of quantitative readjustment of *medical treatment* dollars (Newhouse, 1995), rather than making the more radical moves necessary to reconceptualize them in terms of qualitative changes in the distribution of *health care* dollars.

At what point, after all, does our public commitment to lifesaving begin? Some of the patients in this study had been heroically revived one or more times after being brought into the ED with hypothermia, dehydration, or electrolyte imbalances secondary to malnutrition. We need to extend our most pertinent and vigorous public debate about beginning-of-life and end-of-life policy questions to include middle-of-life policy questions as well. For example, what kinds of assumptions lie behind our bias toward highly technological interventions, when we know that basic food, shelter, and a living wage or income support would ease so much social misery? What would our society look like if our strategies toward the poor focused on inclusion and acceptance, rather than exclusion and control? Why is it that we continue to spend far more, both in dollars and as a percentage of our gross domestic product, than other countries and yet cannot provide health care for all (Schieber, Poullier, & Greenwallk, 1994)?

In Finland, for example, the birth of a new baby is heralded by the arrival of an entire layette provided by the government-run health program, to which all belong. Such a practice affirms society's concern for the well-being of its children and welcomes a new member to the community. In our own country, our policies regarding children are incoherent. We are unclear, for instance, whether or not children are the private possessions of parents or the common investment in the future of the state. Parents increasingly feel they must raise their children in isolation, fearing abuse, violence, and intrusion from outsiders who were themselves often abused and isolated as children. What would it look like if we identified and recovered the kinds of public caring that the Finns' baby layette stands for? How would our social world be different if we revered, respected, and rewarded teachers, who engage us in learning to understand one another, rather than sports and entertainment figures, who entertain us as we watch passively?

We also need to extend our ethical discourse beyond bioethics' positivist and materialist limitations. As Fox and Swazey (1984) pointed out, the emphasis in Western bioethics on individual rights and rational calculation as the means to ethical decision-making favors "seeing" only factors that reinforce prevailing instrumental rationality.

> Qualities and considerations that do not easily fit into a logico-rational and cost-conserving framework of ethicality are either excluded from bioethics or relegated to a secondary and peripheral status within it. "Qualities of the heart" like compassion and caring that elicit generosity have a lesser place in bioethics than the reason-guided "qualities of the mind" that support frugality. The moral economy of bioethics, like its cognitive system, is governed by a notion of parsimony that borders on penury (p. 359).

Bioethics has in this way blessed and reified the coalescence between biomedicine and market views of health care. It is thus perhaps not surprising that our institutions almost all now support bioethics committees and consultants to help in making care decisions, even as the space for care within those institutions diminishes.

An ethics based on *phronesis*, instead of rational calculation using abstract principles, might offer us a way back into understanding ourselves as mutually interdependent beings who understand the natural and common world as our home, rather than as something to be controlled, conquered or subdued. Flyvbjerg (1992) calls attention to *phronesis* as one of three "virtues" discussed by Aristotle. *Phronesis*, which is commonly but somewhat unsatisfactorily translated as "prudence," is concerned with deliberations about human conduct in particular circumstances, using practical knowledge derived from experience. Such an ethics holds that the study of human beings is manifestly different from other types of study, such as "scientific" quests for universal knowledge or technical efforts toward the production of things; this distinguishes it from *episteme* and *techne*, the other two virtues identified by Aristotle. This is not the place for detailed elaboration of this notion, which Flyvberg and others have discussed, but it is important to understand that there are other ethical traditions within which our systems may be evaluated; we need to critically evaluate our systems within a larger ethical tradition, rather than seeking ethical traditions which merely reify prevailing systems. Part of developing such an ethic might be encouraging and facilitating the involvement of practicing clinicians and "problem patients" in policy development at the highest levels.

This study provides no neat solutions to the complex problems that contribute to heavy use of ED services, but it raises many questions. At what point is the social fabric that binds us one to another so dissolved that the fundament of trust is irrevocably undermined? Can cost-benefit analysis give us answers to this question? If we no longer understand ourselves as our brothers' keeper, to whom do we turn when we are in need, in pain, in despair? We struggle to make our lifeworlds shape our systems, instead of finding ourselves flattened into irrelevance by the systems we have created.

Implications for Research

This study suggests the need for future research involving both substantive and theoretical issues. Regarding the phenomenon of heavy ED use specifically, research is needed that will help us understand why Asian-Pacific Islanders seem underrepresented in this group. Although in a nonprobability sample, one cannot make generalizations, the fact that in settings where the population of Asian-Pacific Islanders is substantial not a single Asian-Pacific Islander was identified as a heavy user of emergency services over several months of fieldwork is, it seems to me, an intriguing finding worthy of follow-up. Is this apparent anomaly related to cultural differences in medical care utilization patterns, social support structures, health practices?

There is also a need for systematically collected data on emergency services utilization. Many state and federal surveys, for example, collect data on hospital discharges and on "outpatient utilization," but ED visits are not often distinguished from other outpatient visits. Beyond its role as a setting for the provision of specialty services, beyond its role as provider of last resort for medical care, the ED is the place where problems anywhere in the health care and social services system are often first revealed. For example, when hospitals begin discharging patients "sicker and quicker" due to limitations on reimbursement, those patients begin showing up in the ED. When outpatient mental health and drug treatment services are reduced or eliminated, those patients, too, appear in the ED. When hospitals close down wings due to inadequate staffing or other factors, patients may "back up" in the ED awaiting inpatient admissions. The emergency department--particularly the public hospital emergency department-- is a key junction for early identification and investigation of health system problems, and systematic collection of data in this area could be of enormous benefit to policymakers and planners.

This research suggests that improvements in community support services and low-technology care might better meet the needs of patients who are heavy users of emergency services. Intervention studies comparing, for example, managed care on a medical model, case management directed from an ED setting, and nurse-run primary care clinics, which are not based on medical models, may hold promise. The needs for recognition and community that were revealed in the stories of patient participants suggest that more than mere medical care is involved in ED utilization patterns.

Studies comparing homeless and housed "frequent flyer" patients might reveal that providing affordable housing or supplemental income, or, when alcohol is a problem, housing combined with alcohol treatment would be both more cost-effective and more compassionate than waiting for patients to develop life-threatening illnesses or injuries, then treating them in the hospital. Further, research is needed to evaluate the influence of economic interests in determining allocation of resources toward low-technology or no-technology care versus high-technology care. For example, what assumptions in resource allocation create situations where foot care for diabetic patients may not be reimbursable, but amputation of the foot is fully covered? Or where time and personnel are not provided for eating assistance in nursing homes, but feeding tubes are reimbursible (Kayser-Jones, 1990)? Financial incentives worked out between academic health centers and high technology industries must be critically reexamined.

In an era when great emphasis is being placed on the development of "report cards" and "outcomes measures," this study points to the need for explicitly considering what *cannot* be measured as well as what lends itself readily to measurement. For example, our inability to quantify something like the tiny incremental moves that led Jack or Charley to make the transition from being a "drain on society," in the words of one of the nurses in this study, to being respected contributors to the well-being of others, means that institutional incentives that encourage caring practices may be regarded as a waste of time. On what temporal scale would we measure "outcomes" on patients like these, for whom everyday life is still fraught with contingencies and dangers? Would we measure Charley's "outcome" after the first endotracheal intubation and intensive care stay, or after the eighth? This is not to suggest that we should not attempt to determine what interventions work better than others, or better than no intervention at all. But it is critical to keep in mind how this emphasis on what can be measured always makes some interventions more visible than others. It may sometimes be the ones we cannot see that make the biggest difference.

Physically linking public health services with ED services is another potentially promising intervention, in areas where there are still public health services to be linked. The key moral question in funding decisions for such research must be whether our aim is to provide care for those who need it or to reduce use and cost of services. Depending on the answer to that question, very different initiatives will be pursued. This study suggests that all such social-engineering strategies, however, will be of limited use in the absence of understanding the contexts within which these measures are introduced.

The issues of chronic illness and dependency, so central to the findings of this study, require further explication (Gerhardt, 1990). How do we deal with dependency in other medical care settings? How do other societies, for example, those in countries with universal health care, address this issue in their policymaking and practices? What should the role of the ED of the future be, and who will define it? More research into how the stigma associated with being a "frequent flyer" may affect care decisions is needed.

Perhaps most critical is the need for research that gives voice to those who are presently silenced in our medical care system and in the larger system. We need studies that help us hear the lifeworld by bringing forth the voices of the marginalized, not because their pain is worse than ours (although it often is), and not because we feel pity for them, or sorry or guilty (although we sometimes do), but because they have much to teach us: their fate is inextricably linked with our own.

We desperately need research that articulates what makes for healthy communities in which differences are celebrated, rather than diffused or denigrated. There are such places in our cities today: blocks, neighborhoods, social and political groups--where diverse individuals are working out in practice what it means to mostly get along with those not like themselves. We need to hear their stories, extend their learning and find language for this kind of public caring. The question of how we can meet the other--whether that other is the ragged, dirty, drunken "frequent flyer" in the emergency room, the immigrant, the person of another race or religion, the aggressive businessman, or the kid who scrawls graffiti on the wall--is the single most pressing question of our time. We are commonly charged with finding a way to understand both our differences from and our links with others. Through our practices, through our education, through our policies, and through our research, we must strive to

> enlarge the possibility of intelligible discourse between people quite different from one another in interest, outlook, wealth, and power, and yet contained in a world where, tumbled as they are into endless connection, it is increasingly difficult to get out of each other's way (Geertz, 1988, p. 147).

To do otherwise is to abandon ourselves to a new kind of despair: one in which our common humanity, rather than being a source of comfort and community, itself becomes the source of terror and isolation. The question we must seek to answer is not whether or not we can control and dominate our inner impulses and our world, but whether or not, being human, we can be good enough to recognize one another as fully human.

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APPENDIX A
FORMAT FOR OBTAINING VERBAL CONSENT

For patient contacts, the following general format was utilized:

Hello, I'm [researcher] and I'm doing a study of emergency room care. One of the nurses mentioned that you have been a patient here before and I'm wondering if you would be willing to talk with me for a few minutes about your experiences as a patient. I'm especially interested in talking with people who've been here a lot, since they have had the most experience with the place. Talking or not talking to me will not affect your care in any way, however. I am not working for the hospital in doing this study.

If the questions bother you in any way, just say so and I will stop. I would like to ask your permission to [audio]tape our conversation so that I will not have to take written notes. If you agree, you will not be identified in any way on the tape. You can just ask me to turn the tape off if it makes you uncomfortable. I will not use your name on anything written and I will do everything I can to protect your privacy. The purpose of the study is to help understand the needs of patients and hopefully find ways to improve their care.

APPENDIX B

Information Sheet: Frequent ED Visitor Study

Ruth Malone, RN, MS, CEN, a doctoral candidate at the University of California, San Francisco School of Nursing, is doing a study focusing on patients who use the emergency department (ED) frequently. The purpose of the study is to increase understanding of this group of patients and their needs for care. Ruth will be observing in the ED for 10-30 hours weekly for a period of several months.

Ruth is requesting that ED nurses help with the study by pointing out patients whom they recognize as frequent visitors. If you agree to participate, you will page Ruth when a frequent visitor arrives in your work area and, if possible, provide a brief synopsis of what you know about the patient. Ruth will also be observing general care activities, focusing on these patients. The focus of the observations will be on the usual practices and activities involved in care of these patients, not the practice or activity of any particular nurse. However, if you do not wish your activities to be a focus of observations at any time, you may notify Ruth verbally and your wishes will be respected. No nurse, patient, or any other person will be identified by name in data collection or in the report of study findings. Every effort will be made to ensure privacy and confidentiality. Some direct quotations may be used in writing and/or publishing findings, but these will not be identified as to site or person in any way.

There is no direct benefit to you from participating in the study. It is possible, however, that the findings may help illuminate problems and inform clinical and policy decisionmaking, thereby improving care for these patients.

Risks of participation include the potential for occasional minor disruptions of usual routines or mild distraction related to being observed. As an experienced ED nurse, Ruth will make every effort to be as unobtrusive as possible in observing ED activities. Code numbers known only to the researcher will be used to designate persons participating, to protect confidentiality. No one who refuses participation will ever be identified.

If you agree to participate, you do not need to do anything until the study begins. Even if you initially have agreed to participate, you may withdraw at any time. If you do not wish to participate, or if you have questions or concerns not addressed by this information sheet, you may call Ruth at 510-746-1755. You may also contact Ruth's faculty advisor, Dr. Patricia Benner, at 415-476-4313. If you have comments or concerns about participation, you should first talk with Ruth. If for some reason you do not wish to do this, you may also contact the Committee on Human Research at UCSF, 415-476-1814. You may call collect or write to the Committee on Human Research, Box 0962, University of California, San Francisco, CA 94143.

At a later point in the research, ED nurses may be asked to participate in a small group discussion focusing on the care of these patients. If you agree to participate in a group, you will be given further explanation of that part of the study and asked to sign a consent form.

When the study is completed, Ruth will make arrangements to share findings with interested nurses. Thank you for considering participation in this study.

11/2/93

APPENDIX C
Information Sheet B: Patient

Research Project: University of California, San Francisco
______ Hospital Site

You have been asked to participate in a study of patients who have used the emergency department (ED) frequently for health care. Ruth Malone, RN, MS is a nurse researcher from University of California, San Francisco who is studying the care of patients in the ED. The purpose of the study is to increase understanding of the needs and care of patients who use the ED often. You have been asked to participate because you have been a patient here several times before.

If you agree to be in the study, the following will occur:
Ruth will talk informally with you about your experiences as a patient in the ED and other related topics. Ruth will take notes or audiotape the conversation for accuracy. You can stop participating at any time, or you can decline to answer any question. Whether you participate or not, it will not affect your wait to be seen by a health care provider or affect your care in any way. Ruth may, if needed for the study, review previous medical records of your visits in the ED.

Risks of participation may include feeling uncomfortable about talking about your experiences. However, you will be able to stop talking at any time. You can decline to answer any question. Participation in research may involve a loss of privacy; however, your records will be handled as confidentially as possible. Only Ruth will have access to your study records and audiotapes. After the discussion has been transcribed from the tapes, with no names attached, the tapes will be erased. No individual identities will be used in any notes, reports, or publications that may result from this study.

There will be no direct benefit to you from participating in this study. However, the information that you provide may help nurses and doctors better understand the needs of patients who depend on the ED for health care.

There will be no costs to you as a result of taking part in this study. You will not be paid for your participation.

If you have other questions or concerns about the study, you can ask Ruth or you can call Ruth at 510-746-1755, or you may call her adviser, Dr. Patricia Benner, at 415-476-4313. If you have any comments or concerns not addressed by this information sheet, or about which you do not wish to talk with Ruth, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8 a.m. and 5 p.m. Monday through Friday, by calling 415-476-1814. You may call collect or write to: Committee on Human Research, Box 0962, University of California, San Francisco/ San Francisco, CA 94143.

If you are interested in the findings of the study, you may contact Ruth. Thank you for considering participation in this study. 11/2/93

APPENDIX D
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN RESEARCH
______HOSPITAL SITE

A. <u>PURPOSE & BACKGROUND</u>: Ruth Malone, RN, MS, CEN, a doctoral candidate at the University of California, San Francisco School of Nursing, is doing a study focusing on patients who use the emergency department (ED) frequently. The purpose of the study is to increase understanding of this group of patients and provide insights that could improve their care. I have been asked to participate in a focus group portion of this study because I am an experienced ED nurse and am familiar with patients who are frequent ED users.

B. <u>PROCEDURES</u>: If I agree to be in the study, the following will occur:

I will meet in a private area with Ruth and five or six other nurses and we will have a conversation about patients who use the ED frequently. I may be asked to share a story from my experience. An audiotape will be made of the group's conversation. The focus group will last about one hour.

C. <u>RISKS/DISCOMFORTS</u>:

1. I may feel self-conscious about being audiotaped or about talking in front of others about my experiences. I understand that there will be no identifying names used on the videotape or on transcripts and that after the study is completed, the tapes will be erased.

2. Some of the questions or the discussion may make me uncomfortable or upset, but I am free to decline to answer any question or to stop participating in the discussion.

3. Confidentiality: Participation in research may involve a loss of privacy; however, my records will be handled as confidentially as possible. Only Ruth and her transcription assistant will have access to the audiotapes. No individual identities will be used in any reports or publications that may result from this study.

D. <u>BENEFITS:</u> There will be no direct benefits to me from participating in the study. It is possible, however, that the findings may help illuminate problems and inform clinical and policy decisionmaking to potentially improve care for these patients.

E. <u>COSTS:</u> There will be no costs to me as a result of taking part in this study, except the loss of my time.

F. <u>PAYMENT</u>: I will not be paid for participation in this study.

G. <u>QUESTIONS:</u> I have talked to Ruth Malone about the study and have had my questions answered. If I have further questions, I may call her at 510-746-1755. I may also contact Ruth's advisor, Dr. Patricia Benner, at 415-476-4313. If I have any comments or concerns about participation in this study, I should first talk with Ruth. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8 a.m. and 5 p.m. Monday through Friday by calling 415-476-1814. I may call this number collect or write to: Committee on Human Research, Box 0962, University of California San Francisco, San Francisco, CA 94143.

H. CONSENT: I will be given a copy of this consent form to keep.
PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as an employee at _______ Hospital.

If I agree to participate I should sign below:
Date______________
Signature of Study Participant__________________________________

Date______________
Signature of Person Obtaining Consent____________________________

11/2/93

APPENDIX E

Brief Interview Guide, Patients

The following questions are meant to be as broad as possible in order to elicit narrative accounts reflecting the patient's perspective, as opposed to specific answers to the questions themselves. Not all questions will necessarily be asked of all informants.

Hello, I'm Ruth Malone and I'm doing a study of emergency room care. One of the nurses mentioned that you have been a patient here before and I'm wondering if you would be willing to talk with me for a few minutes about your experiences as a patient. I'm especially interested in talking with people who come here frequently. Talking or not talking to me will not affect your care in any way, however.

If the questions bother you in any way, just say so and I will stop. I would like to ask your permission to tape our conversation so that I will not have to take written notes. If you agree, you will not be identified in any way on the tape and when my study is done the tapes will be erased. You can just ask me to turn the tape off if it makes you uncomfortable. I will not use your name on anything written and I will do everything I can to protect your privacy. The purpose of the study is to help understand the needs of ED patients and hopefully find ways to improve their care.

[If patient consents]:

Tell me about yourself.

How did you get to the hospital today? and/or, What prompted you to come today?

Why today rather than...?

What do you think they can do for you today?

Do you have any worries about coming here?

I'm wondering if you think it is better to have come here before rather than to come here for the first time. Is anything different for you as an "old hand" versus people who are new patients?

Where else do you go for health care? How does coming here compare?

What don't you like about coming here? What do you like?

What are your living circumstances? Do you have a family?

For more extended interviews:

I wonder if you have any stories about your experiences coming here. Does one visit stand out in your mind?

Did anything good ever happen to you on a visit here? Anything bad?

Are there any times when you are more likely to come here than other times?

Do you think of yourself as a healthy person?

What is your biggest worry about your health?

Possible other questions will be guided by patients' answers and observational findings.

11/2/93

APPENDIX F

Group Interview Questions, Nurses

As most of you know, I'm doing a study on patients who come to the ED a lot. Today I'm interested in hearing what you have to say about this because as nurses you are the ones who really get to know some of these patients.

I'm wondering if any of you would share a story from your experience that deals with this situation. Is there anybody that really stands out in your mind as an example of this type of patient? Or a really memorable event involving a patient who comes to the ED a lot?

Possible probes: What did you do? Has that happened to anybody else?
Does anybody have a "worst case scenario" story about one of these patients?
Can anyone share a story about a "favorite" patient who comes in a lot?
Are there any patients who taught you something, gave you a new viewpoint?
Are there any "success stories"?
Did anyone ever have a conflict with somebody else over the care of one of these patients; for example, a conflict with another nurse, a doctor, a social worker, a shelter worker, a family member?
Are there any ways you haven't mentioned that you have seen people try to intervene with one of these patients?

What do these patients have in common?
If you could redesign EDs/health care, how would you change what we do with patients like the ones we have been talking about?
Is there anything else that should be done about this situation?
Probes: What should government do?
What should individuals do?
What should hospital administration do?

APPENDIX G
SAMPLE FIELDNOTES

Fieldnotes 10/28-29/94 9:30 p.m.-7:30 a.m.
Lobby observation
Transcribed 10/29/94 RM

I am dressed in old clothes, many layers, topped off by an old knit cap that I have pulled low over my ears and eyes. I carry a plastic grocery bag with a few things in it. I have no ID with me and I brought only 75 cents along. I have T. drop me off. I am very apprehensive about doing this, fearful of discovery and exposure and fearful, too, of being there in this place this way. Anything could happen. I am not going to be the one in control tonight.

I arrive in the lobby about 9:30 p.m. The TV is on as always. Some drama I don't pay too much attention to. I am feeling very anxious and self-conscious about being here like this but no one even bats an eye as I come in with my plastic bag and plunk down on one of the black metal seats. There are seats for 27, in little benches of 2 and 3 individual seats. On my way in, I notice that there are three people outside sleeping on the benches, wrapped in blankets, and one man sitting up in the corner where the outside bench meets the doorway. Inside there are several people sitting around, one person laying down with his bare feet sticking out of the blanket he has wrapped around his body. I go to the restroom. Nobody looks up. There are about 20 people in the lobby. At first I am the only Caucasian. There are a couple of small children waiting with a man who is probably their father. One slightly drunk Hispanic man who comes in shortly after me carrying a nice-looking blue backpack and seems very friendly. He comes and sits next to me and says "how ya doin'?" but when I do not respond, only shrug and nod my head silently in acknowledgement and look back toward the TV, he moves on. There is a nice-looking older black gentleman with curly hair sticking out from underneath a navy blue baseball-type hat, wearing a nice looking grey jacket; he is sitting rather prominently upright in the center seating spot that was Mike's favorite when he was frequenting the lobby. I don't see him here tonight. There is another, slightly stockier and younger, black man wrapped in a brown coat, and an older and very disheveled old black man slumped in another seat, his pant legs dirty, his sweater dirty, his hair mussed up. There is an Asian man with two women who may be sisters.

About 10:30, just as I am feeling "settled in" to begin observations, I see the nurse X. heading out to the lobby. He stops by one man across from me and says, "what's your name? Are you waiting to see the doctor?" I fear I will be recognized and/or unable to keep a straight face and/or that they will look at my band (I had obtained a blank yellow band to wear for this observation time) and see no name. I quickly scuttle around the corner into the rest room. Behind me I hear X. saying "Miss? Miss?" but I pretend I do not hear him. I stay in the bathroom about 20 minutes and then emerge, but when I come out I see X. across the room with the security guard, and as I emerge X. points at me. I head for the door to the outside. "Miss! What's your name?" the security guard says. I put my head down and head out, saying nothing. "Oh, well, I guess she doesn't want to stay," I hear X. say behind me.

Outside it is dark. I sit down on the bench about 12 feet away from the man in the corner, who is holding a big plastic bottle of Coca-Cola between his knees. After a few more minutes, another man, a slender white/Hispanic looking man with a long scarred face, comes and sits about 12 feet on the other side of me. He is smoking a cigarette. Three or four rather better-dressed people are sitting and smoking near the entrance, talking and laughing with each other. The three of us on the bench sit each alone, me looking intently off into the middle distance of the parking lot and trying to avoid catching the eye of either of my benchmates. I clutch my plastic bag to my lap. I watch well-dressed people coming and going briskly, to and from work; it is almost 11 now and time for the shift change.

The man with the backpack who had said hi to me now emerges from inside. I see him shoulder his pack and head off across the parking lot. About 20 or 30 minutes later he comes back and goes back in.

The man in the corner with the bottle of coke has periodically muttered something to himself. Now he abruptly breaks forth in song. He sings softly and really rather melodiously in the darkness: "And it seems like total destruction is the only solution...ain't no use, nobody can stop it now." After he stops singing one of the better-dressed people by the entrance who has been walking around a small lighted area turns back to his companions. "Why don't you come over and kick me?" the Coca-Cola man calls out from his dark corner. "Punch your lights out." The distance and darkness are just enough that the other man cannot hear or at least it is easy to pretend he does not.

An older woman dressed in kitchen worker garb walks briskly past. "Little late tonight," observes the Coca-Cola man in a friendly tone. He is smoking a cigarette. The man on the other side of me bums one from him, says he found the one he was smoking on the ground.

I go back inside. The guard is in the lobby and I see X. heading for the lobby again so I head straight for the bathroom. I write notes in one of the stalls while I wait for it to be 11:30 when I know X. will be off. In the restroom there are 3 stalls, none of which has a latch on the door. The toilet seats are dirty. There are no paper towels and just one small, smeared mirror. It looks like somebody threw up recently on one of the toilet seats. I feel like a small frightened animal scuttling back and forth.

A nurse comes out and calls out a name. The barefoot guy in the blanket yells, "Yeah!" and sits up slowly, yawning. He looks beneath the seat for his shoes, gather then slowly, puts them on, reaches for a plastic bag with other things in it. The nurse stands with her hand on her hip for a few moments, then says, well, just come through that door when you're ready. She goes back in. He slowly finishes gathering his stuff, wads his blanket up and goes back after her.

11:45 p.m.: The guy with the backpack is back when I emerge to the lobby. He puts his backpack down on the floor by the seat. Over the microphone they are calling out patients' names. A woman near me yells across the lobby: "wake her up!" and the man with the long coat, who I notice has crutches underneath his seat, nudges a sleeping black woman who is lying on the chair/benches underneath the TV set. Apparently her name was called. She awakens rather grudgingly and slowly gathers her clothing about her. I don't see a yellow band on the man with the crutches, although the woman looks to have one. An Asian man who seems to be waiting with two women who could be sisters eyes me rather pointedly and suspiciously and makes low comments to his companions. I think he knows that I am just hanging out.

The older black man in the grey jacket is still sitting up very straight. He has a yellow band on his left wrist. He's reading a magazine now, has been there since I arrived. The long-faced man who sat to my right on the bench has now come back inside too and is looking sleepy. The backpack fellow lies down on the floor, using his pack as a pillow. After only a few minutes, though, a security guard (all the guards seem to be black men tonight) walks back through the lobby and yells loudly, "Hey, guy! You gotta get up now! Sit up on the bench or find someplace else to go!" "Okay, I'm getting up right now," the backpack man responds politely. He leaves his pack on the floor, gets to his feet and goes into the bathroom.

I am reading several old copies of "Vegetarian Times," which seems to be the only reading material available in the lobby. The pictures of the food look wonderful. I think how few of the other people there in the lobby even have a home to go home to, much less a kitchen and all the ingredients to make healthy, nutritious meals. It is a little cold and drafty and I am glad I wore all the layers, although the wool sweater and hat are making me itch.

At 12:15 a.m. there are only seven people left, not counting me. The others are the backpack man, a younger skinny black man, very alert, the overcoat man with the crutches, the older black man with the grey jacket, a Hispanic man who appears to be holding something under his coat, a black woman lying down on the bench, and the long-faced man. The TV blares on.

At 1:30 a.m. the security guard comes around again with a 2-1/2 foot long wooden stick and raps it on the metal seats where people are lying down. He tells them they have to sit up. The grey-jacketed man has not ever laid down; he seems to know he must stay upright. The rest of the group have conversed with each other intermittently, though the TV is on so loud I can't hear much. Every once in awhile somebody gets up and changes the channel on the TV. No one pays any attention to me. The people who appear to be staying seem to be concentrated in the seats least visible from the triage and registration area. One man's name is called; he goes to the triage window, returns to his same seat holding a prescription bottle, and sits back down.

There are 3 vending machines in the lobby with sodas and cookies/snacks. Five of the other people are now asleep. A few other people have drifted in. A young volunteer dressed in his light blue jacket comes out and sits down next to the older black man with the grey jacket. He reads a piece of a newspaper for awhile and then watches TV. The barefoot man has returned and wrapped himself up in the blanket again.

At 2:10 a.m. the backpack man is asleep on the bench with his head on his pack, snoring loudly. An inpatient with an IV on a pole has come down and is chatting with the long faced man I saw outside. They go outside and both return in about 10 minutes.

2:30 a.m.: The man with the coat has taken it off and covered his entire head with it. He sits upright on the chair/bench with his coat covering his head. A young Caucasian couple, well-dressed, comes and sits in front of me on the middle section of chairs.

At 3 a.m. as I am reading a piece of the New York Times Magazine that I found under a seat, a black man with long ratty-looking hair comes in and says to me in a very pushy way, "I want to trade seats with you so I can sit next to my wife, okay? You sit there so I can sit here next to my wife. This is my wife, see? We're together. You go over there, okay?" He is dressed in a faded blue pinstripe jacket and dark shiny pants. I say, no, I want to stay where I am. I have now positioned myself in the best place from which to observe everything in the lobby and be very inconspicuous as far as the staff, and I don't want to give it up. I point out that there are two other seats together across the room, but he is very insistent. His wife, a younger black woman dressed nicely in jeans and carrying a little black purse, comes and sits down next to me.

The man persists, insisting that I must trade with him and go sit somewhere else. But I don't want to give up my seat. It is partly my researcher self not wanting to relinquish my observation post and partly the character I have assumed the role of, a homeless mentally ill woman: I feel myself coming to her defense, and I resent his assumption that he can just push her around. I say, no, I was here first and this is my seat, you can sit over there, there are 2 seats together. No, I won't move, I am going to stay here, I repeat. I don't want to move, I don't want to move. This is my place, this is my place, this is my seat.. I feel my heart pounding and my face getting red. I sit stick still. He then squeezes himself in between his wife and me and sits down, opening a bag and taking out hamburgers, which he and his wife begin to eat. "We don't want to eat in front of everybody," he says when I again point out the other seats. His wife is laughing and looking at me. They seem to be very amused that I will not move. At one point he gets up and walks away, then comes back and says, "you make a very nice couple," to me, alluding to me and the wife, and again says, come on, you sit over there and let me sit with my wife, and then sits down again between us.

I am very angry. By this time there are other open seats with 2 together, but they continue sitting there squeezed on top of me. I say, you guys could sit in those seats, but you just want to hassle me. Why do you want to hassle me? I don't want a hassle. I just want to sit in my seat. This is my seat, my seat, my seat. I feel a real stake in this territory and I also suspect that they just want this spot to sleep in too because it is the least conspicuous. They laugh at me and the man notices my yellow band peeking out from beneath my sleeve. "You just waiting to be called, huh? So you'll probably be called back soon," he says. "Maybe," I reply distantly. They laugh. After they finish eating and sit there awhile longer he says to the wife, "want to go have a cigarette?" and they go outside, leaving their wrappers and paper bags on the seat and the floor. They already bought sodas from the machine so they clearly have more money than most of the folks in there tonight do.

I feel a sense of mixed relief and fear as they go out. Relief that they have left me alone and fear at a sudden realization that I challenged a stranger in circumstances where I could have put myself in danger. What if he comes back in and shoots me? I decide this is probably unlikely but I still feel enormously tense. I decide it is probably best to look as non-confrontational as possible so I assume a position of feigned sleep, waking up intermittently and looking vaguely at the TV, where some kind of weird night of the living dead type horror movie is now on; zombies are approaching the house as the inhabitants are boarding up the windows from inside and setting things on fire to scare the zombies away. The couple comes back and they sit down across from me; they seem to have lost interest in tormenting me. The woman who was nudged awake earlier has now returned to her position, bringing with her a bag lunch or maybe two; she shares these with others by putting the sandwiches on top of the garbage can and others walk over and take a piece of bun, a piece of meat. She tosses her carton of milk to the young slender guy, who catches it expertly.

When next I slide my eyes open, a few moments later, a big sheet cake box has appeared on one of the empty chairs and several of the people, including the couple, have helped themselves to big slabs of chocolate cake with white icing. Moments later a young well-dressed black guy comes out from the hall where the rest rooms are. He says something indicative apparently of surprise; the man of the couple says, oh, was that your cake? I thought somebody donated it. There is a small conversation, apparently it was the remains of the young man's birthday cake that he is carrying with him. He doesn't seem too upset but a couple of the older men file up past him on their way to throw napkins in the garbage can and mumble polite thanks to him for sharing the cake. He sits down, cuts himself a piece of his cake, and begins writing something on a piece of paper. It occurs to me to wonder if he is a young sociology student or something, doing the same thing I am, but he seems utterly unselfconscious about having anyone look over his shoulder at what he is writing, so I decide that may not be the case. I would get up and look myself but I am still wary of losing my seat to the pushy couple.

At 4:45 a.m., two security guards come into the lobby, turn off and unplug the TV set, rap the metal chairs with their batons and say, everyone waiting for someone or to see a doctor has to go on the other side of the partition, we're going to clean the lobby now. The young white woman protests that she is waiting for somebody and she is told rather harshly that then she needs to go over behind the divider. Everyone dutifully gathers up their stuff and goes either over on the other side of this low dividing wall or outside. The couple that tried to move me out has fallen asleep. They are rousted too with the batons to the metal chairs. "Time to go, time to go," says the security guard. A very big fat black man, the housekeeper, is there with a mop and bucket. I go into the bathroom and jot a few notes.

The bathroom is filthier than it was the last time. There is vomit on 2 of the 3 toilets and no toilet paper left at all except in scraps on the floor. I feel very powerless and still a little afraid of the couple who tried to take my seat. When I go back out everyone is still waiting and the big janitor is mopping. The Hispanic guy who has been here all night is standing around with something still under his coat. After awhile I realize it is something that looks a little like a small neck pillow, although he never takes it out I see glimpses of it. I am relieved; I was beginning to wonder if it might be a weapon. He has been talking intermittently with another Hispanic man carrying a brown paper parcel which he holds tightly. They go together into the bathroom hallway at one point, then come back out together and the one man leaves. The couple have fallen asleep on the floor beneath the 3 pay telephones. The backpack guy is still there; he tries to bum a cigarette from me but I tell him truthfully I don't have any. The older black guy with the grey jacket is still there too.

After the janitor finishes mopping he takes his mop and bucket and heads down the hall past the restrooms. No one makes a move to go sit down again, however. The floor is still wet. As if out of respect for his efforts, no one proceeds back to their seats until a few minutes later, when the janitor comes back out and says, "Okay, you guys can go sit back down now." Then everyone scoots back to the chairs where they had been before, with the exception of the couple, who remain asleep beneath the telephones.

All the magazines are gone now, swept away in the cleaning. There are just the black metal chairs. The TV remains off. I can hear pop music playing from somewhere but can't tell where. People's names are still being called on the loudspeaker as they have been all night. The security guard comes back out and wakes the couple up. The man says he is waiting to be seen. The guard says, what's your name, and tells him they called him 3 times and he didn't answer so he will have to reregister. I cannot see the scene but I hear loud voices of the man, 2 security guards and maybe the registration clerk. The guard is obviously losing patience. The man comes and sits down in the lobby. "What I want is a apology," he says. The guard says, "Look, you have to reregister, and so you either go back to triage right now or you get escorted out." With some more protest, the guy goes back, then returns a few minutes later to the lobby, climbs up on a chair, plugs the TV back in and turns it on. He then goes into the bathroom.

Meanwhile, the guard has roused the woman, who was still sleeping on the floor, and she has moved back to her former place across from me, where she is lying down across 2 seats. The man comes out in a few minutes and he lies down on 2 adjacent seats. Some news is on now, interspersed with political ads accusing candidates of lying and not caring.

At 6:25 a.m. the door on the other side of the restroom hall is apparently opened, and from that hall emerges a young white man, a little emaciated as though suffering from AIDS or cancer, clad in shorts and a loose shirt. He sits down in a corner and stares vacantly at the TV. The older black man with the dirty pants and the older black man with the clean grey jacket are still here, both sleeping in their respective places. The TV is a show about a brand new megastore, with more computers, TVs, VCRs and everything else than you can imagine. "It took me all day just to walk through it," effuses the man on the TV. "335 different models of TVs, 136 models of washer-dryers."

By 7 a.m. a few more people have arrived, obviously patients waiting to be seen. They are different from the denizens of the night; they are more lively and animated. Those who have spent the night here are immobile, quiet, asleep or awake. It is just beginning to get light outside as I walk out. The man with the Coca-Cola bottle, apparently having spent the night outside in his dark corner, is just heading off across the parking lot as I emerge. He heads quickly down the block. The air is cool and I feel safe now, walking away to my life.

Thoughts: How I am used to feeling more powerful and more important, how everything in that environment works to make you feel insignificant and unimportant and voiceless and in some way unworthy, from the dirty bathrooms to the brutal triage and

registration process with your name called over the microphone and the batons rapping on the metal chairs. Can this be an environment of familiarity and relative comfort? Yet it seemed in some way to be; the people who were staying the night seemed to respect each other, except for the couple who pushed me, and made small remarks to each other. There was the sharing of food and the mutual hassles of being told to move on, etc. The older man with the grey jacket was a kind a patriarch, respected by others. The seat he was in is the same one as Mike's. I wonder if there is some tradition around this.

Fieldnotes 11/5-6/94 9:00 p.m.-4:30 a.m.
Lobby observations
Transcribed 11/6/94

It's a very rainy night, the first of the season, and a Saturday night. Dressed in my bulky layered clothes and knit cap I arrive at the ED lobby about 9 p.m. The lobby is crowded and as usual the TV is blaring. As I sit down in an empty chair, a big bald black guy with an earring says, excuse me, I was sitting there, that's my chair. I say, oh, this is your chair? And get up; he sits down and I take instead the chair where he had been sitting, adjusting his shoes, when I came in. Next to me is another black guy, thin and wiry, who seems to be talking to himself.

I don't see anyone I recognize right off except maybe one black guy, youngish, who was here last time. The older well dressed man and the older unkempt man aren't here. B18 isn't either. A number of people are asleep, some with coats laying across their laps. On TV is footage of Ronald Reagan's 82nd birthday celebration as the announcement is made that he has Alzheimer's disease. A Latino man is sleeping beneath a blanket which looks to be one of the hospital bath blankets. There are a number of side conversations, most of which I can't hear over the TV, but at one point a Caucasian man, in his 20s, who appears in the lobby naked from the waist up with a sheet draped around his shoulders, trousers, and bare feet, dragging a sort of cart with something that looks very much like a round picnic sized drink jug, calls across to one of the black guys sitting in the center row of chairs, in a friendly way, saying, "Where's your brother?" "In the bar," is the reply, and both laugh. On TV now is film of George Foreman again winning the boxing title with a tenth round knockout. This generates a flurry of conversation: "Look at that old guy," "Yeah, a knockout," etc.

The man with the sheet pulls out some sort of food and tosses it to a couple of the fellows sitting in the middle row of chairs. Three people now have sheets or blankets which they pull up around their shoulders. More people filter in.

At 12:15 there is a TV show on about spontaneous human combustion. No one seems to be paying much attention. Those with sheets and blankets have pulled them up over their heads. There are about 22 people sitting down and several more standing around, including some well-dressed people who look like they were out for the Saturday night. They seem to be waiting for someone; as new people join their group they apprise them of what they know. The people in the lobby pay no attention to them either.

Two black men, about 40-50 years old, are sitting side by side on the chairs where I sat last time and they are clearly parked there. They have their shoes beneath the chairs and their plastic bags and there is a pile of refuse under the chairs. Now the man closest to me takes out a jar of peanut butter and a slice of bread and begins eating.

A thin black man in inpatient gown and robe comes in with his IV pole. He chats with several people in the lobby and then goes out with another man, apparently to have a cigarette; they smell of smoke when they return. It is still raining. The thin black man leaves.

At 1:30 a.m. an inpatient couple, both dressed in hospital robes, come down and first are unable to get change for the soda machine, leave, and return, buying a soda. They sit down beside me on a chair and the metal table that connects my chair with the other one. Shortly after they sit down, a security guard asks them to leave, saying "there's no place for people to sit." The place has really filled up, almost all seats are taken. The couple shrug and leave. A slightly built barefoot black man is asking people if they have a lighter. Somebody gives him one and he goes outside.

A black woman whom I recognize as a f/f (the one who said "Mama!" to the case manager) is there, barefooted also; she approaches a well-dressed Caucasian woman in minidress, long coat and high heels and asks her for money for a sandwich. "You just had a sandwich," replies the woman. "Sorry, but I had to call you on it." The black woman moves away and the well-dressed woman resumes her conversation with her friends. Someone else puts some money in the soda machine and it does not function properly. A black man is hitting the machine. The Caucasian man with the sheet around his shoulders says, "I got a gun; you want to put a bullet in it?" No one pays any attention to this.

At 2 a.m. the place is packed and the crowd is mostly awake, enjoying a black comic on TV. The black men laugh and nudge each other. An older Asian couple have arrived and taken seats beneath the TV set in the far corner. They look about at the scene anxiously. Two young women arrive to wait with a third. The two who arrive are soaking wet. They give a cigarette to the one waiting.

At 2:30 p.m. one of the black men on the far row of chairs who has been there since before I arrived gets up and goes out, leaving his duffel bag on the table by his seat. A Latino man, new to the scene, arrives and sits down in the chair just vacated by the other man. A black man sitting in what I might call "The Mayor's" position, tells him that's somebody else's seat, look, there's his bag, but the Latino shrugs, sits down and pulls his jacket up over his chest. Shortly thereafter the black man returns. He goes up to the Latino and tells him it's his chair. The Latino is ignoring him. He reaches out and grabs at his arm, but the Latino shoves it away. I hear something said about "Pedro" and "Maybe he doesn't understand." There is a sense of growing tension. The man in the next chair, a Caucasian bundled up in sweatshirt and long jacket, assiduously gives the appearance of being asleep, despite the rising tone of the talk. The big bald black man with the earring who had at first told me to sit elsewhere suddenly rises and walks across to the Latino. "Maybe he understands sign language," he says, and roughly grabs the man's arms and bodily lifts him out of the seat. Nobody moves. The Latino leaves and the black guy that had been sitting there before sits back down.

Shortly, a security guard says, can I talk to you a minute? to the big black guy with the earring. He takes him over by the door. The guard, a policeman, is an Asian man, shorter and smaller than the earring guy, with a gun holstered prominently on his belt. "I understand there was a problem here," I hear him say, and cannot hear the rest until I hear him say, "Well, when it comes, you are out of here."

The atmosphere is increasingly lively as it approaches 3 o'clock. Another f/f I recognize, Sam, comes into the lobby area. The smell of urine is very strong as he passes by. Earlier, a black male janitor had come around with a broom. The denizens of the lobby dutifully lifted their feet to let him sweep under the chairs but did not get up.

At 3 a.m. two security guards come around and say, okay, anybody without a yellow band or not waiting for someone needs to leave. One of them checks the band of the man sitting next to me; I position my wrist so the band peeks out and pray he doesn't check for my name, and he doesn't, he nods and moves on down the line. He asks the 2 young girls who they're waiting for and they give him a name; this apparently satisfies him and they stay. A number of the others are rousted out, about half of the people. They go out. A couple of them, including the man who was trying so hard to appear asleep during the fight over the chair, drift back in after the guards move on.

One of the two men on the chair where I sat last time, the one who had been eating peanut butter, grumbles to another man that "it's the bums that wreck it for the rest of us." He has shown the guard his unfilled prescription and told him that he has to wait until morning to get it filled because they won't fill this kind of medicine at night. He seems rather proud to have this prescription form to wave around; he puts it carefully back into his pocket after the guard goes on.

There are a number of exchange transactions throughout the course of the night. Cigarettes are traded or sold for food, the peanut butter man's spoon is borrowed, one man goes around looking for a light; someone lights a small cigar he carries and he heads out, smoking. The peanut butter man and his companion make plans for "going down there tomorrow" with the big black man with the earring.

By 4 a.m. the older Asian woman is fast asleep in her corner chair, her husband having been called back a couple of hours ago. "Planet of the Apes" is on TV. The guards stroll back and forth behind the partition occasionally. There is a big puddle under the chair where Sam was sitting, I notice after he gets up and goes to the restroom.

An Asian family--mother, daughter, and probably son--have been talking in the hall area by the entrance. They have been here for several hours. Now the mother begins to cry softly. The daughter hugs her. They lean against the wall. There are no vacant chairs. The earring guy is still in his chair. Also present is a Caucasian man with greasy-looking long hair and a big poncho who, when the guard earlier checked his band, said, "don't touch me!" in an affronted tone and was told by the guard that he had better shape up or he would be asked to leave.

At a few minutes after 4 an announcement comes over the loudspeaker that the MAP van is here. A couple of the men get up and go out, including the earring buy. At 4:10 I decide to leave. I walk around to the other door so I will be less likely to run into anybody. It is still raining steadily. The sprinklers are on over the lawn area by the ambulance drive, even though it has been raining all night. I watch for awhile, but I don't see any of the people who got kicked out earlier. The benches, wet and windswept, are empty.

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