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The Making and Meanings of Difficult Patients: Doctors' and Nurses' Subjective Understandings and Experience of Difficulty

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DEDICATION

I dedicate this dissertation to my partner Steven. He was a rock of stability and support throughout this project.

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ABSTRACT

The Making and Meanings of Difficult Patients: Doctors' and Nurses' Subjective Understandings and Experience of Difficulty

Norman Fineman

This dissertation investigates how health care providers in their everyday practices with patients and with each other construct meaningful understandings of difficult patients, and examines what those meanings are. The study has three principal goals: (a) to build a systematic and comprehensive typology of providers' descriptions of patient difficulty; (b) to identify and account for differences in providers' descriptions of patient difficulty; and (c) to shed light on how doctors experience difficult patients, particularly behaviorally difficult patients, in their everyday lives.

The study utilizes methods for conducting intensive, empirically grounded, naturalistic field research. In particular, this dissertation follows in the tradition of ethnographic studies that utilize interpretivist/constructivist approaches as a means for studying the process of meaning-making in professional settings, and for examining the subjective and experiential meanings of practitioners' everyday work worlds. Data derive from detailed long-term observations of three clinical settings in an urban, community hospital, a series of in-depth interviews with doctors, nurses, and patients, and investigation of patient case studies.

The central findings of the dissertation are the following: First, providers' understandings of difficult patients are multiple, complex, and often (but not always) shared. Doctors and nurses describe difficult patients in terms of a wide variety of medical conditions, personal and life circumstances, and unexpected behaviors, all of which serve to complicate caregiving, obstruct rapport building, and evoke negative feelings.

Second, the dissertation exposes as unreliable the common presumption in medical research that health care providers view patient difficulty in essentially the same ways. In fact, providers' understandings of difficult patients are marked by regular and systematic differences that relate to their status, level of training, self-perceptions of their roles and responsibilities, and expectations of appropriate patient behavior. This observation sets to rest the myth that difficult patients are universally recognizable and identifiable primarily on the basis of specific patient characteristics.

Third, the dissertation suggests that doctors experience behaviorally difficult patients as threats to their sense of professional entitlement and empowerment. This observation, by speaking directly to the ways in which doctor-patient interactions are dynamic, constructed, and negotiated, thus exposes as overblown the insistent claim of much medical sociology and anthropology theory that doctors exercise total power in doctor-patient encounters.

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CHAPTER 1

INTRODUCTION

A good deal of medical research on doctor-patient interaction as well as many reports by doctors and nurses contend that difficult patients are an objective, self-evident, and conspicuous category of problem patient. Underlying this contention are three important assumptions about the construction and meanings of difficult patients: (a) the presumption that patients are the primary locus of difficulty; (b) the presumption that health care providers are able to recognize and accurately identify difficult patients with ease; and (c) the presumption that providers' perceptions about difficult patients--specifically, their understandings about who is and who is not difficult--are widely shared by their peers. Despite the popularity of these propositions, no systematic research has ever demonstrated that any of them are actually so.

This dissertation aims to critically examine the ubiquitous medical claim that difficult patients are self-evident and conspicuous. It does so by investigating some of the bases by which doctors and nurses socially construct and "know" patients as being difficult. It also investigates providers' subjective experience of difficult patients. In short, the dissertation investigates how health care providers in their everyday practices with patients and with each other construct meaningful understandings of difficult patients, and examines what those meanings are. The study utilizes methods for conducting intensive, empirically grounded, naturalistic field research. Data derive from detailed long-term observations of three clinical settings in an urban, community hospital, a series of in-depth interviews with doctors, nurses, and patients, and investigation of patient case studies.

The study has three principal goals: (a) to enumerate all the ways in which doctors and nurses at the research site subjectively and meaningfully described patients as difficult; (b) to identify differences in the ways in which these providers described difficult patients, and by doing so, examine some of the bases on which their descriptions of difficulty depend; and (c) to shed light on how doctors experience difficult patients, particularly behaviorally difficult patients, in their everyday lives.

Although related, the goal of investigating the processes by which providers construct subjective, meaningful understandings of difficult patients, and the goal of explicating what those meanings are, are distinct research tasks, which often required the use of diverse methods of analysis. As a consequence, the dissertation embraces a variety of analytical tools, which include both structural and phenomenological analyses, and qualitative and quantitative methods. The examination of how providers construct understandings of difficult patients, for example, depends on a systematic structural analyses of providers' definitions and descriptions of difficult patients. This analysis employs both quantitative and qualitative methods to identify and explain differences by status and level of training in how providers describe and define difficult patients and relates these differences to differences in providers' behavioral expectations of patients and self-perceptions of their professional roles. The point of this analysis is to try to precisely document two of the ways in which health care providers socially construct difficult patients in daily practice.

Examination of the experiential meanings of difficult patients to providers, in contrast, relies on an intensive phenomenological analysis of providers' experience of difficult patients. This analysis examines the meanings of doctors' expectations of patients and relates these meanings to their experience of patient difficulty. I suggest that difficult patients threaten doctors' senses of control and authority, and expose their dependence on patients' cooperation. Paradoxically, they serve at the same time as a means for doctors to publicly communicate and assert authority and control. In order to uncover some of the ways in which doctors understand and express their threatened status, I introduce the notion of *idioms of conflict.* I use this metephor as a means of revealing and examining doctors' emotional and strategic responses to behaviorally difficult patients.

To tie these disparate analyses together, I draw on an overarching theoretical framework that encompasses a number of different interpretivist and constructivist social science approaches to the study of everyday life. I believe that this framework integrates the related interests of the dissertation by providing a consistent conceptual basis for the entire enterprise. In the main, the project is guided by an abiding respect for the problematic and constructed nature of social reality, an understanding that social reality is produced and maintained in interaction and experience, and an attentiveness to the manner and meanings of wielding power in provider-patient interactions.

The dissertation is organized into four main sections. Section I includes the three introductory chapters to the study. Chapter 2 discusses the theoretical and substantive contexts of the dissertation. It begins with a description of the dissertation's theoretical framework, which sketches the scope and content of constructivist/interpretivist studies of doctor-patient interaction and locates the place of the dissertation in those studies. Following this, the chapter critically examines four bodies of existing empirical research about doctor-patient interactions and interactions with difficult patients.

Chapter 3 describes the methods used in the dissertation. The chapter begins with a description of the field site, which includes descriptions of the hospital and the three clinical research settings, and description of hospital staff members and patients. Following these, it then describes in detail the sources of data, and the procedures used to collect, code, and analyze data. Finally it discusses briefly relevant methodological issues of this project including gaining entry and rapport, defining generalizability, validity, and reliability.

Section II examines how and why providers perceive patients as difficult. Using interview and observational data, aggregate nominal data, and case studies, it describes and illustrates providers' shared and everyday understandings of difficult patients. The practical aim of this section is to build a systematic and comprehensive typology of patient difficulty from providers' perspective. In doing so, it establishes the foundation for investigating the constructedness of patient difficulty and the personal, experiential meanings to doctors and nurses of difficulty in their practices. The central observation of these chapters is that providers' understandings of difficult patients are multiple, complex, and often (but not always) shared. Chapter 4 focuses on describing providers' understandings of medically difficult patients, and details six conceptual domains of medical difficulty: cognitive/psychiatric problems; problems of chronicity; problems of uncertainty; multiple medical problems; and absence of cure. Chapter 5 examines the domain of circumstantial difficulty, and details two conceptual domains of circumstantial difficulty: circumstantial problems of patients' lives, and circumstantial problems of their care. Chapter 6 examines the domain of behavioral difficulty and describes seven conceptual domains of difficult behaviors: obstructive behavior; manipulative behavior; abusive behavior; challenging behavior; attention-seeking behavior; crazy-making behavior; and irresponsibility.

Section III examines some of the bases on which doctors' and nurses' understandings of patient difficulty are constructed. The principal observations of this section are that providers' understandings of difficult patients are marked by regular and systematic differences related to providers' status and level of training, and that these differences are associated with specific factors of providers' own lives and practices. In other words, the section illustrates some of the precise ways in which providers construct patients as being difficult, and thus demonstrates how providers are themselves a locus of patient difficulty.

Chapter 7 investigates the ways in which doctors and nurses, attendings and residents, and RNs/nursing administrators and LVNs differentially conceptualize patient difficulty. The analysis identifies four ways in which providers' understandings of difficulty vary predictably and systematically according to their status and level of training: (1) doctors report significantly more difficulties than nurses because they cite more instances of behavioral difficulty; (2) interns', residents', and attendings' understandings of difficulty are alike, but LVNs' and RNs' understandings of difficulty are different; (3) RNs report significantly more medical and total difficulties than LVNs; and (4) RNs, but not LVNs, report significantly more circumstantial difficulties than doctors. The subsequent two chapters attempt to account for these observations.

Chapter 8 seeks to examine and explain the observation that doctors cite significantly more behavioral difficulty than nurses. I argue that providers' understandings of behavioral difficulty are tied to their behavioral expectations of patients. Indeed, their behavioral expectations of patients are good predictors of the behaviors they perceive and describe as difficult. Specifically, I argue that providers perceive and report as difficult those behaviors that deviate from their expectations of appropriate, proper, and normal patient behavior. The chapter then documents that doctors have more and more-difficult-to-meet behavioral expectations of patients than nurses. These, I suggest, are the reasons they cite more behavioral difficulty than nurses.

Chapter 9 seeks to similarly examine and explain the observations that interns', residents', and attendings' understandings of difficulty are alike, but LVNs' and RNs' understandings of difficulty are different; that RNs report significantly more medical and total difficulties than LVNs; and that RNs, but not LVNs, report significantly more circumstantial difficulties than doctors. The chapter examines and compares the domains of doctors' and nurses' self-perceived roles and responsibilities, the differences between them, and the ways in which these differences are related to their understandings of difficulty. I argue in this chapter that providers' perceptions of difficulty are associated with their self-perceptions of their appropriate professional roles. Specifically, I suggest that providers generally perceive as difficult those patients who hinder them from performing their roles, and perceive as not difficult those patients who help them to perform their roles or who are irrelevant to the performance of their roles.

Section IV focuses on doctors' experience of behaviorally difficult patients. The two chapters of this section examine in depth doctors' phenomenological experience of difficult behavior and behaviorally difficult patients. By this I mean that I examine the personal, individual, and subjective meanings of behavioral difficulty and behaviorally difficult patients that providers construct in their everyday experience and in their ordinary affairs and interactions with patients and with each other. The central observation of these chapters is that doctors experience behaviorally difficult patients as a threatened sense of empowerment. Chapter 10 building on the discussion in chapter 8, examines the experiential meanings of doctors' expectations, and the implications of those meanings for their understandings of behavioral difficulty and for their experience of behaviorally difficult patients. I suggest that doctors experience behaviorally difficult patients as a threatened sense of empowerment. The argument is supported by a logical sequence of direct and inferential evidence that affirms three points: (a) doctors expect patients to trust them and respect their rightful authority (b) doctors perceive lack of patient trust and lack of respect for their authority as difficult behaviors; and (c) doctors ultimately experience loss of trust and authority as a threatened loss of power.

Chapter 11 examines doctors' experience of behaviorally difficult patients more intensively. To do so, it draws upon the notion of idioms of conflict as an analytical device with which to clarify and enlighten doctors' experience of behaviorally difficult patients. The chapter begins with brief introduction and review of the use of idioms as a means of exploring issues of phenomenology. It then describes in detail the case of a quintessentially difficult patient whose outrageous behaviors serve as a springboard for investigating doctors' experience of behavioral difficulty and their use of idioms of conflict as a means of understanding and expressing this experience.

Statement of Problems and Questions Asked

This dissertation focuses on the problems of how health care providers subjectively understand and experience some patients as being difficult. It asks the following related descriptive and interpretive questions:

(1) How do doctors and nurses define and understand patients as being difficult?

- (1a) Are there patterned differences in the ways in which doctors and nurses define and understand patients as being difficult?
- (1b) Are there patterned differences in the ways in which interns/residents (in-training doctors) and attending physicians (out-of-training doctors) define and understand patients as being difficult?
- (1c) Are there patterned differences in the ways in which LVNs (in-training nurses) and RNs/RN administrators (out-of-training nurses) define and understand patients as being difficult?
- (1d) If so, what are the factors that account for these differences?

(2) By what means do doctors and nurses construct their understandings of difficult patients? What is the meaning-making process that underlies their assessments that patients are difficult?

(3) What is the essence of doctors' experience of difficult patients?

- (3a) How is this experience made known to themselves and others?
- (3b) What does doctors' experience of difficult patients reveal about their perceptions of their interactions with patients?

(4) What if any social functions do difficult patients serve?

CHAPTER 2

THEORETICAL AND SUBSTANTIVE CONTEXTS

Introduction

The questions asked and issues raised in this dissertation are discussed in a number of noncontiguous research literatures that examine provider-patient interactions and interactions with difficult patients theoretically and empirically. Although these bodies of research are similar in that they attempt to understand what happens in interactions between providers and patients, they differ significantly in that they approach the subject at different levels of analysis, with different overarching political frames of reference, and use different theoretic perspectives and assumptions, different sources of data, and different methods of investigation and analysis. They are as a result not easily summarized or synthesized, and I make no attempt to do so here. This chapter is a focused and critical review of the theoretical and substantive contexts of the dissertation. The chapter has two aims: (a) to serve as a meaningful context in which to view the empirical findings of this dissertation; and (b) to build a rationale for the utility of the dissertation--to show, in other words, why the study is timely and important.

The chapter begins with a description of the dissertation's theoretical framework, which sketches the scope and content of constructivist/interpretivist studies of doctor-patient interaction and locates the place of the dissertation in those studies. Following this, the chapter critically examines the substantive contexts of the dissertation. Specifically, I review existing empirical research on doctor-patient interactions and interactions with difficult patients. This review examines four bodies of research: (a) biomedical/medical services/public health studies of provider-patient communication and interaction; (b) provider self-assessments of interactions with patients; (c) anecdotal provider reports of difficult patient interactions, difficult patient relationships, and noncompliance; and (d) discourse and conversational analyses of provider-patient interactions. The chapter concludes with a brief review of two relevant models of provider-patient interaction.

Theoretical Contexts: A Review of Social Science Research on Making and Interpreting Meanings in Everyday Life

My Theoretical Stance

This dissertation investigates how health care providers in their everyday practices with patients and with each other construct meaningful understandings of difficult patients, and examines what those meanings are. A principle goal of the study is to shed light on how providers experience difficult patients in their everyday lives. In order to carry out this investigation, the study draws on a wide range of approaches that Schwandt (1994:118) has loosely referred to as "constructivist/interpretivist approaches to human inquiry," and that Douglas (1971) has called social theories of everyday life. I use these terms interchangeably to refer to the conceptual approach I use in this dissertation.[1]

The domain of everyday social theory is difficult to define with precision. It is a body of research with ambiguous boundaries, with disparate perspectives and methods, and without systematic integration among its constituent parts. Its origins are various and it draws upon the interests and perspectives of five separate fields of study including (1) phenomenological and existential philosophy (see for example, Husserl 1931, 1988; Merleau-Ponty 1965; Schutz 1962, 1964); (2) symbolic and interpretive anthropology (Geertz 1973; Turner 1974) and anthropological linguistics (Conklin 1962; Frake 1962); (3) social psychology (Cooley 1967; Mead 1934); and critical sociology (Gouldner 1971; Mills 1961). In this dissertation, I define social theory of everyday life to encompass four theoretical approaches: ethnoscience,[2] phenomenology,[3] symbolic interactionism,[4] and ethnomethodology[5].

Few current statements systematically review the domain of everyday life social theory or recognize it as a unified theoretical approach. Four important exceptions include Adler, Adler, and Fontana (1987), Douglas (1971), Psathas (1971), and Schwandt (1994). Each of these writers has discussed social theories of everyday life as a domain, either as a loose collection of related perspectives (Adler, Adler and Fontana 1987; Schwandt (1994) or as a distinctive body of theory (Douglas 1971; Psathas 1971). They do not agree, however, on precisely which theoretical perspectives constitute the domain.

Despite their diverse sources, the social theories of everyday life that shape the perspectives and methods of this dissertation are unified by a number of fundamental shared premises, perspectives, focuses, and aims. I believe that these underlying shared qualities bind the diverse theoretical perspectives discussed here into a unified approach to the study of everyday social life.

First, all of the perspectives mentioned stand as critiques of conventional structural/functional sociology and assert the ambiguity and arbitrariness of orthodox sociology concepts and methods. They reject positivism, abstract empiricism, rational objectivism, and survey methods. In addition, they reject the Parsonian view of the primacy of a normative and rule structured social order and the presumption of a stable social system of shared meanings and norms external to and independent of human consciousness, experience, and interaction. Instead, they are concerned with matters of knowing and being, and aim to look beyond idealized rules and norms of behavior to investigate what people actually think and do in everyday life, and to carefully attend to the "details, complexity, and situated meanings of the everyday life world [by] watching, listing, asking, recording, and examining" Schwandt (1994:119).

Second, they all share two central focuses: (1) a microfocus on individuals; and (2) a focus on the ways in which people construct, interpret, and affirm meanings in everyday social life.

Third, they all deal with similar conceptual problems. These include: the nature of reality and social order, the relationship between knowledge (meanings) and action (behavior), the interpretation, creation, maintenance, and categorization of meaning and meaning-making, and the relationship between individuals and society.

Fourth, they all share fundamental theoretical premises: They view social meanings, and by extension, social reality as being socially constructed in everyday life; (they differ, however, in how they propose that meanings are constructed); they all view everyday social life as being the source of all meanings; they generally view meanings as being problematic rather than stable and dependable; they generally view social meanings as being the determinants of social action, and view social action as an intentional meaning-making activity; and they generally regard the social world as being inherently reflexive.

Fifth, they all reflect a spirit of humanism by stressing the emergent, processual, and voluntaristic character of human behavior and by focusing on the "becomingness" of human existence, social organization, and social relations. They all view human beings as active, creative builders of social reality.

Sixth, they all share use of compatible methods which are intensely emic, qualitative, and largely empirical.

Seventh, they generally share epistemological concerns regarding the nature of social science knowledge and (with the possible exception of ethnoscience) actively work towards the creation of a self-reflexive and self-critical social science.

What marks social theory of everyday life (or any theory for that matter) as a unique form of inquiry is the set of assumptions it mandates about how the world is ordered, how reality is construed, and how we are able to know about them. In an effort to make my assumptions as explicit as possible, I detail them now. These are the theoretical and methodological assumptions I make:

(1) Like Schwandt (1994:126), I assume that "what we take to be objective knowledge is the result of perspective," that knowledge, truth, and meaning are constructed (in subjective experience and interaction), not discovered. But I am not antirealist. To the contrary, like Miles and Huberman (1994) and Schwandt (1994), I hold that social reality exists in an objective world as well as in the mind, and that the reality that people construct in experience and interaction generally corresponds to something in the real world.

(2) I view human behavior as purposive, and I regard people as generally autonomous, intentional, active, and goal directed; People construe, construct, and interpret their own behavior and that of others, and through interaction and experience they actively participate in creating themselves and their worlds.

(3) Following Cicourel (1964, 1968) and Garfinkel (1964, 1967), I assume that people in their everyday activities attempt to make sense out of their world, and that these sense-making activities are grounded in common sense knowledge of the natural attitude, comprise the essence of social action, and are observable through use of naturalistic, ethnographic, and emic anthropological field methods.

(4) I assume that common sense knowledge is produced and affirmed in everyday reasoning, action, experience, and face-to-face

interaction (Blumer 1969; Cooley 1956; Cicourel 1964, 1968; Garfinkel 1964, 1967; Mead 1934)

(5) I assume that people act toward things on the basis of the meanings that these things have for them (Blumer 1969).

(6) Like Garfinkel (1967), I view social order as being produced and affirmed on an ad hoc basis in everyday action and reasoning based on people's taken-for-granted expectancies of behavior.

The Place of This Research in Existing Research

This dissertation conforms with Nader's (1969) call to "study up," and is located in the large and growing ethnographic literature that focuses on examining biomedical clinical beliefs and practices, and the work of Western clinicians. Ethnography has been used previously to examine a variety of clinical topics including differences between patients' experiences of illness and practitioners' medical understandings of disease (Kaufman 1987); the social construction of noncompliant and difficult patients (Conrad 1987, 1985; English and Morse 1988; Fineman 1991a; Lorber 1975; Wright and Morgan 1990); doctor/elderly patient interactions (Greene et al. 1986, 1987; Kayser-Jones 1981); and the transaction of power in doctor/patient relations (Becker and Nachtigall 1991; Wright and Morgan 1990).

In particular, this dissertation follows in the tradition of ethnographic studies that utilize interpretivist/constructivist approaches as a means for studying the process of meaning-making in professional settings, and for examining the subjective and experiential meanings of practitioners' everyday work worlds. Such studies have previously investigated, for example, the social organization of clinical practice (Gaines and Hahn 1985; P. Katz 1981) and the domains of medical knowledge (Becker et al. 1961; Hahn 1985); and have examined the construction of experiential meanings in a variety of clinical settings including an operating room (P. Katz 1981); a stroke rehabilitation unit (Kaufman and Becker 1991; Kaufman 1987); a cancer unit (Germain 1979); in-hospital surgical training and practice (Bosk 1979); in-hospital internal medical practice (Hahn 1985); and medical school (Becker et al. 1961). This dissertation extends previous work by investigating ethnographically the meaning-making activities of doctors and nurses in three clinical settings.

The present study also falls broadly within the parameters of two ethnomethodological research traditions: first, it focuses on how people experience and depict the social world as being factual, a topic of investigation that Berger and Luckmann (1967) have broadly referred to as the social construction of reality; and second, it focuses on demonstrating how social order is created and sustained on an ad hoc basis.

Research of the first type aims to describe the work that people perform to generate a sense of objective reality about their world. In previous work, this research has described the construction of a large number of diverse categories of social reality including: the social construction of moral meanings (Douglas 1970) and emotions (Harre 1986; Lynch 1990); the social construction of ethnicity (Lock 1990); the social construction of scientific fact (Latour and Woolgar 1986) and medical knowledge (Wright and Treacher 1982); the social construction of gender (Garfinkel 1967) and sexual identity (Gilmore 1990; Kitzinger 1987; Weinberg 1983); the social construction of medical records (Garfinkel 1967) and time in medical interactions (Frankenberg 1988); and, in particular, the social construction of categories of deviance (see Douglas 1971b), particularly the social construction of deviance by professional groups. These have included, for example, the construction of juvenile delinquents by courts (Cicourel 1968), the construction of criminals by public defenders (Sudnow 1965), the construction of bad students by school officials (Cicourel and Kitsuse 1963) and the construction of difficult or noncompliant patients by health care and social service providers (Fineman 1991a; Murcott 1981). In each case, this work has viewed deviant individuals not as natural social types, but rather as products of the professional agencies that define and control them. This dissertation, in an identical way, argues that difficult patients are not natural types, and demonstrates how they are socially constructed by providers.

Research of the latter tradition, aims to demonstrate how people cooperatively produce social order. Previous work has demonstrated the production of social order in a number of different contexts including: standing in line (Livingston 1987), reaching a verdict in a jury room (Garfinkel 1967), creating meaning from arbitrary and faked patterns of responses (Garfinkel 1967); turn-taking in conversation (Sacks 1972, 1981), identifying and managing juvenile delinquents (Cicourel 1968); and peacekeeping on skid row by police officers (Bittner 1967). Very often, in order to shed light on the common-sense criteria upon which people assess their everyday, common-sense understandings of reality, this work has paid particular attention to the ways in which people make decisions in everyday situations, especially in ambiguous situations.[6] Sharing this aim, the present study examines the ways in which doctors and nurses decide who is and is not difficult as a means of revealing the common sense moral criteria they use to distinguish between acceptable and unacceptable patient behavior.

Finally, the present project follows in the tradition of previous phenomenological studies all of which aim to describe and elucidate the meanings of human experience. Because phenomenology attends to the reality of lived experience, it provides a means of describing and clarifying fundamental aspects of human experience. To this end, phenomenological studies have investigated subjects' own categories of meanings as a way of uncovering the reality of their subjective experience. Such studies focus on the reality of the self as it is experienced by people in their everyday lives.

Phenomenological research has examined peoples' experiences of many phenomena including illness,[7] embodiment,[8] and aging.[9] But to my knowledge, no research to date uses phenomenology to investigate health care providers' experience of difficult patients. The present study aims to help fill this gap in the literature.

Substantive Contexts: A Review of Empirical Studies of Provider-Patient Interactions

Although problems of physician-patient interactions have been widely discussed for many years, informed discussion of them has until recently "taken the form of rhetoric, exhortation, and policy pronouncements rather than of analysis based on direct observation" (Mishler 1984:8). Systematic observation and analysis of provider-patients interactions actually began in the mid 1960s, but as Waitzkin (1984) observed, this research was fairly uninformative until about 1974. Even today, the substance and utility of empirical studies of provider-patient interactions are severely limited by a lack of theory with which to explain findings and by serious methodological and epistemological problems.

This review is restricted in scope and intent. It is neither a general introduction to nor a survey of the field of empirical studies of provider-patient interaction. Detailed and comprehensive examination of all substantive studies of provider-patient interaction is beyond the interest and needs of this dissertation. I limit this review to four principal bodies of empirical research on doctor-patient interactions and communication: (a) biomedical and allied studies of interaction and communication between providers and patients; (b) providers' and patients' self-assessments of interactions; (c) providers' anecdotal reports of difficult and noncompliant patients; and (d) conversational and discourse analyses of provider-patient interactions.

Type I: Biomedical/Medical Services/Public Health Studies of Provider-Patient Communication and Interaction

Overview. Biomedical/medical services/public health studies of provider-patient communication and interaction represent a vast and confusing body of research. Although many reviews of this research literature have been undertaken during the past 15 years (see for example, Hall et al. 1988; Mathews 1983; Ong et al. 1995; Roter and Hall 1989; Tuckett and Williams 1984; Waitzkin 1984; and Wasserman and Inui 1983), a resulting synthesis is lacking.

Studies of this type use a standard biomedical research design of independent-dependent variables in which various measures of interaction (such as providers' interactional style, content of interaction, affective qualities of interaction, level of information exchange, level of patient participation in problem solving)[10] are defined as the principle independent variables (they also use several sociodemographic characteristics of patients as independent variables),[11] and outcome measures of "interactional success" and "quality of health care" such as compliance and patient satisfaction are defined as dependent variables.[12] The meaning and significance of interaction patterns are then interpreted in terms of degree of association with the dependent variables.

In order to define and measure interactions, an important and frequently used strategy of these studies is to code and analyze a series of clinician-patient interactions in terms various proxy measures of communication that measure aspects of provider and patient utterances and nonverbal behavior.[13] These studies thus understand provider-patient encounters as episodes of information transfer that occur on multiple levels (i.e. content, cognitive relationship, affective relationship), and are based on the dubious assumption that if interaction on all of these levels is systematically analyzed, the nature of the encounter can be revealed. A number of analytical systems (also called observation instruments) have been developed and used to code communication in provider-patient interactions.[14]

Critics of biomedical studies of interaction (see, for example, Tuckett and Williams 1984; Waitzkin 1984) point out that they are plagued by biomedical biases. These include a dedication to examining only interactions between doctors and patients, although there are exceptions (see, for example, Jarrett and Payne 1995, which selectively reviews empirical research on nurse-patient communication), and an uncontested dependence on several taken-for-granted biomedical assumptions, among them the unquestioned authority of doctors to seek out and enforce medical goals in patients' interest, the correctness of medical definitions of disease, and the power and correctness of medical practices. While the immediate aim of this research is to code minute aspects of interaction in order to analyze the process of interaction between providers and patients, the larger aim of these studies is to identify and examine ways for providers, especially doctors, to "improve" interactions by recognizing barriers to interaction (see, for example, Quill 1989) so that they are better able to obtain accurate and medically useful information, provide information to patients and ensure that patients understand it, arrive at treatment plan with which patients concur, modify patients' health beliefs and behaviors, and assure patient compliance (See Sanson-Fisher 1989; Golden et al. 1995).

Findings, The predominantly exploratory nature of this research, in which various measures of interaction are correlated with various outcome measures and various personal and demographic characteristics of providers and patients, contributes to an overwhelming number of results. In short, findings of this body of research are voluminous, fragmentary, disparate, and oftentimes trivial. In very general terms they suggest that physicians who share information with patients in understandable language, listen to their patients' concerns and allow them to talk, evidence sincere concern for patients in body language and voice, and are courteous and respectful, encourage patient satisfaction and aid compliance.[15] But as Tuckett and Williams (1984) and Hall et al. (1988) have pointed out, few theoretically important or statistically significant relationships between interactions and outcomes have been established and the field does not show progress.

Type II: Providers' and Patients' Self-Assessments of Interactions

Overview. Research reporting on providers' and patients' self-assessments of interactions are similar to those described above in that they utilize biomedical research designs (and measure the same observational and outcome variables), reflect biomedical aims of identifying and trying to resolve physician-defined problems of communication, and express biomedical perspectives and biases. But rather than reporting on outside observers' records of medical encounters, this body of research investigates patients' and providers' own reports of events during the medical visit.

Typical of these studies are Bowman et al. (1992), which asked patients to rate the quality of their interactions with their doctors and correlated these with assessments of satisfaction; Ramos (1992), which asked nurses to assess their relationships with their closest patients; Anderson and Zimmerman (1993), which examined how chronically ill (diabetes) patients' perceptions of their relationships with physicians related to their satisfaction; and Lock et al. (1989), which investigated dialysis patients' perceptions of success and failure in communication.

Findings. As with Type I studies, providers' and patients' self-reports of interaction in medical encounters display a dizzying (sometimes contradictory) array of findings that are at once seemingly obvious and difficult to interpret.

Waitzkin (1984) and Waitzkin et al. (1976, 1978) report that patients have a very high desire for medical information and want to know almost everything. Other researchers point out, however, that patients' desire for information is conditional on a number of diverse factors including their desire for sympathy (Coser 1962)[16]; their perception that staff members are busy and overworked, their perception of a high degree of social distance between themselves and staff, or their perception that nurses lack authority to communicate information; their fear of providers' negative reactions to questions; their inability to understand medical jargon (Skipper 1965)[17]; and the success or failure of procedures performed on them (Lock et al. 1989).[18] Bowman et al. (1992) found that patients' reports of high levels of satisfaction correlated with reports of high scores in interaction. However, other researchers have found that this observation, too, is tempered by other factors. Anderson and Zimmerman (1993), for example, report that patients with lower levels of education are most satisfied; that confusing or contradictory information is the most important source of patient dissatisfaction with medical care (Mathews 1983); that patents are more satisfied when they receive nontechnical explanations of medical problems, education, and stress counseling, (Brody et al. 1989).

Anderson and Zimmerman (1993) found that physicians who view relationships as partnerships have more satisfied patients than those who view the relationship as physician-controlled. Nevertheless, doctors' self-reports suggest that they are often unaware of (or unwilling to admit to) their interactional styles. As a group, they believe that they spend much more time medically informing patients than they actually do. Information-giving by physicians, however, is variable and is influenced by demographic factors such as physicians' level of income and class background. Waitzkin (1984), for example, found that doctors usually underestimate patients' desire for information, underrate (in comparison with patients) the clinical usefulness of information giving, spend little time giving information--a little more than one minute in a 20-minute encounter; and overestimate by nine times the amount of time they perceive themselves to give information to patients. He also reports (1984) that doctors who earn less money tend to spend more time informing patients, and that doctors from upper- or upper-middle-class backgrounds tend to spend more time informing patients, give more explanations, and provide more nondiscrepant responses than doctors from lower-class backgrounds

Reporting on nurses self-assessments, Ramos (1992) found that nurses assess as most beneficial those relationships that they rated as having the most intense levels of attachments, which they defined as characterized by mutuality and reciprocity.

In sum, biomedically oriented studies (Type I and Type II) suggest that patients value and desire understandable medical information, but their ability to ask for it and physicians' willingness to supply it are influenced by factors of patients' medical status, age, ethnicity, level of education, and social class, and by their perceptions of the medical staff and the clinical setting. These studies also suggest that patients want empathy and are most satisfied with medical care when physicians attend to them with sincerity and concern.

Type III: Providers' Anecdotal Reports of Difficult and Noncompliant Patients

Overview. Health care providers consider difficult patients to be a major problem of clinical practice. Physicians and nurses consistently report that such patients obstruct their work (Lorber 1975), consume too much of their time (Podrasky and Sexton 1988), and engender negative feelings of anger, frustration, inadequacy, and impotence (American Family Physician 1989; Crutcher and Bass 1980; Malcolm, Foster and Smith 1977; Podrasky and Sexton 1988; Schwenk et al. 1989). In a survey of 722 patient-physician interactions, Crutcher and Bass (1980) found that physicians perceived 30 percent of their interactions with patients as being difficult.

A large number of anecdotal reports describe provider perceptions of difficult and noncompliant patients. Such patients may be referred to alternatively as "heartsink patients" or "complex" (Carson et al. 1993), as "problems" (Greengard 1991; Malcolm et al. 1977), or even as "hateful" (Groves 1978). These reports are typically written by doctors and nurses in clinical practice and have practical rather than theoretical objectives in mind, which include identifying for other providers who difficult patients are, alerting them to the hazards of dealing with such patients, and offering helpful suggestions and guidelines for managing their difficulty. While a few of these reports attempt to investigate difficult patients within some conceptual and analytical framework, for example, as a breakdown in communication between physician and patient (Schwenk and Romano 1992) or as a failed relationship (Shahady 1984; Staley 1991), more often these reports serve as catalogs of difficult patient attributes in which patients are assumed to be universally recognizable and identifiable on the basis of specific diagnostic criteria. With rare exceptions, the authors of these reports view patients--especially patients whom they perceive to be difficult as a result of some unacceptable behavior--

as the primary source of difficulty. As a consequence, they often hold such patients accountable and blame them for being difficult. In general terms, this body of work attributes difficulty to one or more of three patient factors: (1) demographic characteristics; (2) characteristics of patients that render them unable to be helped; and most commonly, (3) unacceptable behaviors. Although most of these reports originate with and report on doctor-patient interactions, a good deal of research also reports on nurses' encounters with difficult patients (see, for example, Castner 1982; Conlin 1981; Podrasky and Sexton 1988).

Who are difficult patients? Medical, nursing, and social science research all confirm that patients described by providers as being difficult have certain perceived common demographic characteristics: (1) They are likely to be old, over 65 years of age (Chandy et al. 1987; Conlin 1981; Slocum 1989); (2) They are likely to be women, particularly divorced or widowed women (American Family Physician 1989; Chandy et al. 1987; Schwenk et al. 1989; Stimson 1976; Slocum 1989); (3) They are likely to have cultural backgrounds different than those of their providers (Leininger 1984; MacGregor 1967; Ruiz 1981); and (4) They are likely to be classified as either working or lower class (Crutcher and Bass 1980; Stimson 1976).

Patients who are difficult to "help" (Mayou and Sharpe 1995; Sharpe et al. 1994) because they have uncertain or problematic medical diagnoses are also likely to be described by providers as being difficult. Typically, these are patients who: (1) have vague, difficult to describe, undifferentiated medical problems (Crutcher and Bass 1980; Schwenk et al. 1989; Slocum 1989; Stimson 1976); (2) have many or chronic medical problems (Chandy et al. 1987; Slocum 1989); (3) require many tests, office visits, medications, or referrals (Chandy et al. 1987; Crutcher and Bass 1980); or (4) take too much time (Lorber 1975; Podrasky and Sexton 1988; Stimson 1976).

Finally, patients who are perceived to exhibit deviant or unacceptable behaviors may be described by providers as being difficult. Medical and nursing studies catalog a wide array of patient behaviors by which providers identify difficult patients. Such patients are described by providers as being: (1) uncooperative (Carson et al. 1993; English and Morse 1988; Lorber 1975; Podrasky and Sexton 1988; Stimson 1976); (2) demanding or complainers (Carson et al. 1993; Castner 1982; English and Morse 1988; Laurence 1986; Lorber 1975; McMorrow 1981; McNellis 1979; Podrasky and Sexton 1988; Stimson 1976); (3) irresponsible about their health (Katz 1996); (4) overemotional (Lorber 1975); (5) overly dependent or overly independent (Lorber 1975; McNellis 1979); (6) over-active (English and Morse 1988); (7) disruptive, unsubmissive, or resistant (Laurence 1986; Lorber 1975); (8) malingerers (Katz 1996); (9) argumentative (Lorber 1975); (10) manipulative (Carson et al. 1993; McMorrow 1981; English and Morse 1988; Podrasky and Sexton 1988); (11) violent or combative (English and Morse 1988; McMorrow 1981); (12) unappreciative (Gasek 1980; Schwenk et al. 1989; Stimson 1976); (13) stubborn or unreasonable (English and Morse 1988;

Podrasky and Sexton 1988); (14) impolite (Podrasky and Sexton 1988); or (15) noncompliant (English and Morse 1988).

Why are Patients Difficult? Very little research investigates the bases upon which health care providers interpret patients' difficult behaviors. Two exceptions (English and Morse 1988; Podrasky and Sexton 1988) both suggest that nurses interpret patients' unacceptable behaviors on the basis of intent. These studies report that patients were more likely to be considered difficult by providers when patients' unacceptable behaviors were interpreted as being deliberate and conscious.

Much of the biomedical literature pathologizes the deviant behaviors of patients perceived to be difficult and interprets difficult patients as pathological personality types. These studies represent laundry lists of purported patient "personality styles" or "defects" that contribute to difficult physician-patient relationships. Groves (1978), for example, in a widely cited article suggests four categories of behaviorally difficult patients based upon the negative feelings such patients evoke in physicians. These categories include: (1) "dependent clingers" who evoke feelings of aversion; (2) "entitled demanders" who evoke feelings of fear; (3) "manipulative help-rejecters" who evoke feelings of guilt and inadequacy; and (4) "self-destructive deniers" who evoke all of the above feelings plus feelings of malice. Similarly, Block and Coulehan (1988) construct a six-type typology to describe the pathological personalities of difficult patients. These include: (1) "dependent demanders"; (2) "orderly controllers"; (3) "dramatizing manipulators"; (4) "long suffering masochists"; (5) "guarded paranoids"; and (6) "superior patients." In a similar way, Schwenk and Romano (1992) identify five types of difficult personalities: (1) "passive, dependent, or over-demanding patients with unrealistic expectations; (2) dramatic, emotionally involved, seductive, affectionate patients with unrealistic need for attention; (3) long-suffering, masochistic, denying patients; (4) somatizing patients with endless complaints; and (5) angry, demanding, and complaining patients.

Medical texts on the subject reinforce the perception that patient difficulty is largely an issue of patients' undesirable or pathological personality characteristics. Although cautioning against over-generalizing, a recent text, for example, (Levinson1987) categorizes difficult patients in terms of "common difficult relationships" that include hostile patients, overly talkative patients, confused, forgetful patients, aggressive, pseudo-independent patients, demanding, dependent patients, paranoid patients, depressed patients, and seductive patients.

Principles of Ambulatory Medicine (Roca in Barker et al. 1995), a comprehensive source book for interns and residents, (which was used as an authoritative resource in the medical clinic where I did the fieldwork for this project) devotes an entire chapter to patients' "maladaptive personalities." In it, the authors utilize categorizations from DSM-III (American Psychiatric Association 1980) to describe 11 types of personality disorder of difficult patients, which are grouped into three personality clusters: the "dramatic" (histrionic, borderline, narcissistic, and antisocial types); the "anxious or fearful (obsessive-compulsive, dependent, passive-aggressive, and avoidant types); and the "odd or eccentric" (schizoid, schizotypal types) and describe management techniques for each subtype.

How are difficult patients managed? A good deal of research describes the strategies that providers use to manage difficult patients. These include: (1) strategies to enforce proper behavior such as behavior modification and reality orientation (Conlin 1981; McNellis 1979); (2) strategies of punishment such as confrontation (Gasek 1980; Groves 1978; McMorrow 1981), retaliation (English and Morse 1988), scolding and reprimanding (Glaser and Straus 1965; Lorber 1975), and bullying and dominating (Gasek 1980); (3) strategies of avoidance and distancing such as neglect, termination of care or early discharge (Groves 1978; Lorber 1975; Podrasky and Sexton 1988; Roth and Eddy 1967); (4) strategies of control such as use of chemical or physical restraint (Cembrowicz 1989, Conlin 1981; English and Morse 1988) or referral for group therapy or psychiatric evaluation (Lorber 1975; McMorrow 1981; McNellis 1979); (5) strategies of compassion such as giving patients "extra attention" and "tender loving care" (Castner 1982), making contracts in which providers commit to not abandon the patient no matter how difficult he or she is (Slocum 1989), and promoting patients' psychosocial as well as physical well-being (Malcolm et al. 1977); (6) strategies that structure provider-patient interactions such as setting limits, defining clear behavioral expectations (McMorrow 1981; McNellis 1979; Conlin 1981) and confining treatment to one complaint (Malcolm et al. 1977); (7) strategies of cooperation such as reassessing and treating difficult patients as new patients (American Family Physician 1989), involving difficult patients in treatment decisions (American Family Physician 1989) and making patients aware of treatment goals (Malcolm et al. 1977); and (8) strategies to improve providers' caregiving such as self-review of consultation behavior (American Family Physician 1989), early detection of problems and avoidance of making early referrals (Malcolm et al. 1977).

Studies of Noncompliance. Noncompliance is defined objectively in medicine as "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) does not coincide with medical or health advice" (Haynes 1979:1; see also Christensen 1978; DiMatteo and DiNicola 1982). It is widely recognized by clinicians as a significant and serious problem of medical practice. Studies estimate that between 30 percent and 60 percent of patients do not comply with medical regimens (Luscher and Vetter 1990; Kaplan and Simon 1990).

Reflecting its significance as a problem, a large body of medical/public health/medical services research focuses on identifying correlates of noncompliance. These have included patients' demographic and personal characteristics (including age, sex, ethnicity, health status, health beliefs and values, and outcome and efficacy expectancies), characteristics of medical regimens (including difficulty and complexity of regimen, duration, intrusiveness), characteristics of medical settings (such as waiting time, continuity of care), characteristics of the clinician-patient interaction (such as information sharing and emotional contact), and, in some cases, physicians' characteristics (such as job satisfaction, number of patients seen per week, tendency to answer patients' questions, specialty.[19] The aim of this research is to help physicians understand, detect, and improve compliance through interventions to modify patients' beliefs and behavior. Yet strangely, despite its prevalence and the apparent ease with which medical research indicates noncompliance should be identified, doctors are unable to predict noncompliance in patients any better than by chance (Norrell 1981; Roth and Caron 1978).

Perhaps this indicates that noncompliance is not the objective and self-evident category that medical research represents it as being. A persuasive body of social science studies (predominantly health psychology and medical sociology studies) supports this position. A good deal of research has focused on understanding noncompliance from patients' perspectives, and views noncompliance as a patient strategy for managing illness or maintaining autonomy (Conrad 1985, 1987a; Hayes-Bautista 1976; Stimson 1976; Trostle 1988; Trostle et al. 1983). In addition, in previous research (Fineman 1991a), I examined providers' subjective understandings of patient noncompliance.[20] This research suggests that noncompliance, like other categories of deviance, is socially constructed and subjectively defined and interpreted. Specifically, it suggests that noncompliance is a provider-constructed category of many and different unacceptable patient behaviors.

In sum, medical and nursing reports of difficult and noncompliant patients suggest that these patients are frustrating problems for physicians and nurses. Given the large number and repetitive nature of studies of difficult patients, and the reliability of the findings they report, these studies give the impression that difficult patients are self-evident, easily identified diagnostic types that are recognizable and definable on the basis of particular demographic, health status, and behavioral characteristics. In short, they understand patient difficulty as essentially a personal and individual problem of and created by patients. But they never actually inquire into the nature or experience of these problems. Instead, studies of this type ascribe problems to patients, based on an empirically abstract concept of pathological or dysfunctional personalities. They also give the impression that there are no differences in the number and kind of ways in which doctors and nurses perceive patients to be difficult and suggest instead that all providers view patient difficulty in identical ways. But no systematic research actually confirms that this is so.

Type IV: Discourse Analysis of Provider-Patient Interactions: Studies informed by Sociolinguistics, Conversational Analysis, Interactionism, Ethnomethodology, and Phenomenology

Overview. Conversational analysis draws heavily on the work of Garfinkel (1967) and may be viewed as a major subfield of ethnomethodology. The premises underlying conversation analysis are exactly those of ethnomethodology: (1) that ways of speaking, like ways of knowing, are problematic and to be discovered; (2) that conversation is a cooperative, negotiated, ongoing interactive process; (3) that analysis begins within the data of speech events themselves; (4) that differences in institutionalized power between speakers, is demonstrated discursively in a variety of ways, and that language use reflects, sustains, and reproduces social structures of dominance; and (5) that a person's competence is not passive or mechanical but part of a strategy for interpretation (Gumperz and Hymes 1972).[21]

Studies of conversational analysis, like those of ethnomethodology, often focus on the demonstration of the problematic and ad hoc nature of social order. Generally, this work investigates the underlying discursive practices that make conversation possible between people of the same culture. Analysis of discourse relies less on analysis of the content of speech than on analysis of the interactional functions of different features of speech such as intonation, hesitancies and breaks in fluency, and other paralinguistic features. It is thus interested in what is being "done" by speakers through their ways of talking, not necessarily what they say. It classifies many nonsemantic and nonsyntactic features as "cues" and views them as carriers of affect that can modify the meaning of words.

Specifically, studies using conversational/discourse analysis have examined how listeners utilize their common sense knowledge of social organization to interpret their conversations (Sacks 1972, 1981) and how speakers cooperate on the basis of shared taken-for-granted assumptions to move conversations along, using such procedures as turn taking (Schegloff 1972), paired utterances (Schegloff 1972), sequencing in openings and closings (Schegloff 1972, 1979), laughter (Jefferson 1979), preference organization (Davidson 1984, Pomerantz 1984), topic organization (Button and Casey 1984), and repair (Jefferson 1979).

Reflecting ethnomethodology's interest in the meaning-making activities of professional groups, conversational analysis has investigated the discursive practices of professionals in practice, particularly those of health professionals and patients (Heath 1981, 1982, 1986); Watson 1981; Meehan 1981). A fundamental underlying assumption of all these studies is that analysis of talk between patients and physicians is a primary source for understanding clinical work.

Findings. The findings of sociolinguistic studies of doctor-patient conversation suggest that doctor-patient interactions, like all interactions, are cooperative and negotiated efforts, and have documented precisely some of the ways in which doctors and patients cooperate and negotiate to repair interactions that are breaking down (see, for example, Heath 1984; Robins and Wolf 1988)[22]. But more importantly, this body of work has pointed out how interactional cooperation and negotiation between doctors and patients is limited by structural asymmetries in power between doctors and patients, and has shed a good deal of light on precisely how such disparities in power are transacted in conversation. These studies do not accept as unproblematic the implicit and pervasive medical biases of Type I studies. Moreover, they explicitly recognize inherent disparities in the level of knowledge and in the roles of providers and patients that are created by formal and informal policies regarding the control of information in medical interactions (Mathews 1983). Doctors, for example, have been observed to use a number of verbal and nonverbal cues to shut down interactions with patients including such cues as shifting topics, continuing to talk and not paying attention to patients' input, interrupting, asking closed-ended questions, using technical jargon, limiting time, or walking away. (See, for example, Cicourel [1981]; Fisher [1984]; Mathews [1983]; Waitzkin and Britt [1993]).[23]

Problems with and Limitations of Existing Empirical Research

The meaning and trustworthiness of the findings reported in the above studies are clouded by serious conceptual, methodological, and epistemological problems, some of which the present study hopes to address. The essential problem with much of the current empirical research on provider-patient interaction and patient difficulty (Types I, II, and III) is that it conceptualizes both topics in very limited and purely objective terms. As a consequence, these studies tend to undervalue the broad social contexts in which medical interactions take place, and virtually ignore the intensely personal subjective experience for providers of dealing with difficult patients. In short, these studies are unable to capture the complexity, dynamism, and nuanced meanings for either providers or patients of difficult provider-patient interactions.

Type I and II studies, for example, erroneously reduce the complexity of provider-patient interactions to arcane, measurable units of "information transfer." Certainly it is questionable whether the quality of doctor-patient interactions is knowable through measures of communication such as "level of information exchange" or "level of patient participation in decision making." But beyond that, the simplistic conceptualization of interaction as information exchange cannot take into account the host of obvious and relevant contextual factors that are essential for gaining a meaningful understanding of medical interactions, and treats all interactions as equivalent. None of these studies, for example, takes into account such factors as patients' health status, how well the doctor and patient know each other or how often they have previously spoken, or patients' attitudes towards doctors and beliefs about medicine. Roter and Hall (1989) documented this problem. They calculated that fully 40 percent of studies of doctor-patient interaction do not even specify whether or not the patients and providers studied know one another. As Garfinkel pointed out years ago (1964), peoples' speech cannot be properly interpreted without knowing something about the biography, purposes, and situational context of the speakers.

Similarly, the conceptualization in these studies of patient compliance, satisfaction, recall or activity as "success in interaction" or "quality of health care" is at best insufficient and at worst spurious. As a number of critics have pointed out, the assumption underlying the use of patient recall as an indicator of success--that patients treat all information as equivalent in importance--and the assumption underlying the use of patient activity as an indicator of success--that patients assume equivalent decision-making roles regardless of health status or severity of disease--are fallacious (Ende et al. 1989; and Pendelton and House 1984; Tuckett and Williams 1984). As a number of authors have noted, in order to study information-giving and outcomes in medical interactions, it is necessary to first have an idea about the possible meanings and purpose of the information to the patients to whom it is given.

The essential problem of medical research on difficult patients (Type III) is that it gives difficult patients (especially difficult patient behaviors) unequivocal ontological status, and thereby misrepresents difficult patients as self-evident categorical types. As a result, most medical studies of difficult patients neglect to investigate the socially constructed order of difficult patients. What counts as difficult behavior--the set of background expectations, norms, and values that are invoked by providers to categorize certain patient behaviors as difficult--are left unexplored. One consequence of presuming that difficult patients are self-evident types is that these studies implicitly assume the locus of difficulty to be the patient, rather than the provider or the health care setting. And consequently, a good deal of the research investigating change strategies focuses primarily on strategies to change patients' behaviors rather than on those to change physicians' behaviors.

In addition, current research on difficult patients is descriptive and anecdotal. No research explains why providers perceive particular patient behaviors as being difficult or why providers choose particular strategies to manage difficult patients. Also, most studies of difficult patients are unsystematic and despite substantial reasons to expect that doctors and nurses might differ in the ways that they define patient difficulty, these studies uniformly fail to inquire about such differences.

Studies of medical discourse and conversation (Type IV) have come a long way to redress some of the serious limitations of positivist research on doctor-patient interaction. Discourse and conversational analysis represents a body of work that tries to resolve some of the deficiencies of health services research, provider self-assessments of interaction, and anecdotal reports. It is theory-based, systematic, and contextual. But its analytical power is limited by its extremely microfocused view of interaction. Methods of discourse analysis focus on observing and/or taping medical interviews and. Unlike ethnography, which often uses fragments of conversation for illustrative purposes, discourse analysis uses the conversation itself as data for methodological analysis. The method is microfocused, paying scrupulous attention to details of transcription and analyzing very small samples, sometimes as little as a single interaction with a single individual. Labov and Fanshel (1977), for example, devote the entire book to a detailed analysis of a single 15-minute segment of a therapy session between a patient and psychotherapist.

The present study, in a number of ways, hopes to make a meaningful contribution to existing applied medical and social science research that discusses provider-patient interactions and difficult patients by dealing with some of the theoretical, methodological, and epistemological limitations, deficiencies, and omissions of previous work. First, the present study is systematic. The proposed study seeks to deal with each of these limitations. It seeks to systematically explain how and why health care providers perceive their patients' behaviors as being difficult, how their perceptions are different, and how they are related to their expectations of appropriate behavior. Second, the study is comparative. It explicitly compares doctors' and nurses' understandings of difficulty, their expectations of behavior, and their experiences of difficult patients to for similarities and differences as a point of departure for analysis. Third, the study is holistic and contextual. It conceptualizes and considers provider-patient interactions within multiple contexts of patients (biography, health status, diagnosis, prognosis, familiarity and prior history with current and former providers, beliefs and attitudes about medical care and interaction), providers (status, level of training, beliefs and attitudes about medical care and interaction), and clinical settings (inpatient/outpatient).

In addition, this project may meaningfully add to the corpus of theoretical social science research that discusses the social construction of reality, deviance, and medical power. Social science research has routinely overlooked the clinician in investigations of patient-provider interactions and typically focuses instead on the patient. The proposed research seeks to redress this imbalance by focusing specifically on the provider. And because this is an ethnographic study, it will report on the provider's point of view.

This research may meaningfully add to the research on deviance and the social construction of reality because it implicitly views difficult patients, like other categories of deviance, as being socially constructed and subjectively defined and interpreted. By and large, difficult patients have been given an unequivocal ontological status. Their behaviors are typically and erroneously treated as being self-evident and objectively defined. As a consequence, research has neglected to investigate the negotiated order of difficult patients. The behaviors of difficult patients have been documented but the ways in which providers perceive, define, interpret and manage these behaviors have not been systematically studied. The proposed study seeks to directly address this issue. By conceptualizing difficult patients as a subjective provider-constructed category of deviance, it will examine the norms, values and expectations of providers that underlie their perceptions of difficult patient behaviors.

The present study may also contribute to our understanding of medical power in clinical practice. By systematically examining the relationship between providers' perceptions of difficult patients and their management and control of patients' difficult behaviors, this study may be able to shed some light on the ways in which medical power is transacted at the level of social interaction.

Endnotes

1 It may seem odd to invoke the works of Schwandt and Douglas in the same breath. Certainly they are not traditionally thought of as representing congruent research paradigms. And I imagine that Schwandt, if asked, would agree with that assessment. Nonetheless, I marry the two traditions here in an effort to stimulate synthesis, to avoid

philosophical faddism, and to eschew what I see as unnecessary philosophical turf battles.

I view the differences between what might be called "old-style" interactionist/constructionist traditions and "new-style" interpretivist/constructivist traditions as just that, differences in style. And I think that new-style researchers often (and perhaps unwittingly) make the case for this position themselves. For one, they often pay homage to old-style forebears including Mead, Husserl, Blumer, Schutz, Geertz, and Berger (see, Schwandt 1994 for example). Second, by their own standards of measurement, the two traditions may be deemed compatible. Guba and Lincoln (1994), for example, use a framework for comparing a number of different research paradigms, which includes a number of assessment criteria, the most important of which are comparing paradigms in terms of their perspectives on ontology, epistemology, methods, and aims of inquiry. It seems to me that along all of these dimensions, old- and new-style paradigms are congruent: Both advocate a relativist, constructed view of reality; both hold to a transactional, subjectivist epistemology; both use emic, idiographic, naturalistic methods; and both aim to provide *Verstehen* by "attend[ing] carefully to the details, complexity, and situated meanings of the everyday life world" (Schwandt 1994:121).

This is not to say that there are no differences between old- and new-style interpretivist/constructivist paradigms. There are, but these differences are additive. New-style paradigms, adopt insights from poststructural philosophy, especially from cultural studies (which connect meaning-making in social interaction to the communication process), feminist critiques (which mandate taking into account factors of gender and class), and critical theory. They add to old-style paradigms explicit new concerns for issues of power and hegemony, thus expanding on the small-scale focus of most earlier work. But these differences hardly render the two paradigms incompatible. Indeed, I think that the differences merely reflect increasing philosophical maturity. In any event, to construe such differences as significant and divisive is spurious. The two paradigms are compatible and complimentary. And this is especially true at the nuts-and-bolts, practical, everyday, empirical level of doing research.

2 Ethnoscience is rarely (if ever) included in current surveys of interpretivist/constructivist approaches to social analysis because its aim--to uncover the "real" meanings in people's heads of cultural categories--is held to be essentially a positivist fallacy. Nevertheless, I include its use here because I find it to be a useful interview method for eliciting people's understandings of the structure of cultural domains. I agree with critics of the approach, however, that its claim to reveal a single structured cognitive reality is patently false. I certainly do not subscribe to its underlying ontological and epistemological assumptions that (a) culture amounts to the sum of a society's folk classifications of the material and social universe; (b) that these classificatory systems reside in the minds of the culture bearers; and (c) that these systems are equally known by all culture bearers and are accessible to inspection by speaking to any member (Sturtevant 1964; Goodenough 1956, 1957).

Ethnoscience (also referred to as ethnosemantics, ethnolinguistics, componential analysis [see Goodenough 1956; Wallace and Atkins 1960] or the new ethnography [see Fried 1968]) encompassed both a theoretical domain and a formal methodology (Sturtevant 1964; see also, Conklin 1962; Frake 1962, 1964; Goodenough 1957). The central tasks of ethnoscience research were: (1) to get "inside" events to see what kind of theory underlied members' own organizational frames and to work out a "grammar" of culture as it was organized in members' heads (Frake 1962; Goodenough 1957); (2) to describe members' systems of classification and to reveal the structural rules by which members ordered their world; and (3) to discover how members actually performed their activities and to describe what meaning they assigned to acts (Psathas 1968). The utility of this approach was that it focused on members' perspectives, it was made up of easily learned procedures, and its results were comparable cross-culturally. The procedures of ethnoscience were well described by Frake (1962, 1964), Conklin (1962), Goodenough (1957) and Psathas (1968).

3 Phenomenology investigates the "meanings of conscious experience" (Welsch 1939:5) and more broadly, the nature of "essential being" (Husserl 1931:46) as it is revealed through the study of conscious experience. It takes the position that the subjective experience of reality, called by Husserl (1931) the "being in the world lived consciousness of reality" is the essence and meaning of reality. Phenomenology thus attends to the reality of experience and provides a means of investigating the experience of individual reality. In doing so it illuminates the everyday common sense world as it is known and experienced (Rogers 1983). This discussion focuses on consciousness as a continuous stream of meaning. It takes the position that through consciousness, people bring everything, themselves included, into existence (see Husserl 1931:112-170; see also good summaries in Lauer 1965b:656-81; Rogers 1983; Welsch 1939). The aims of phenomenology have been described by Rogers (1983). They include: (1) the discovery of the "pure" essence of consciousness and being; and more narrowly, (2) the discovery of the meanings of individual experience.

Two central focuses of phenomenology are: (a) a perspective on the self that treats self as one of many objects given in everyday life, which like all objects is open-ended and constructed; and (b) a discussion of the central theme of the lifeworld (lebenswelt), the mundane world of lived experience, as the grounds of conscious existence and the basis of common sense. This discussion focuses on three features of the lifeworld: (1) its taken-for-grantedness; (2) its sociocultural context; and (3) its paramount reality (see Husserl 1931:101-105; Lauer 1965b; Rogers 1983:47-66). Schutz (1962) described the life world as the taken-for-granted everyday common sense world of social action and consciousness. In particular, he focused on the natural attitude of the life world which he defined as constituting the common sense presumptions that people have about the social world as a taken-for-granted fact.

4 The term symbolic interactionism was coined by Blumer (1937, cited in Blumer 1969:1) and refers to the meaning-making properties of human social action. The theory derives from the work of Cooley (1956), Mead (1934), and Blumer (1969) who provided the clearest formulation of its perspectives and methods. At the time of its initial publication, symbolic interactionism represented a reaction to the prevailing biobehavioral explanations of human action suggested by Freud and Watson that proposed that human behavior was the product of biologically based instincts, needs, and drives. In contrast, symbolic interactionist theory proposed that human cognition, affect, and behavior derived directly from social interaction.

Interactionist theory views society as a consensus of shared meanings in the form of common understandings, expectations, and roles worked out cooperatively and consensually in ongoing social interaction (Mead 1934). It thus views society as a cooperative process of ongoing activity and interaction, a process that consists of making indications to others and interpreting their indications. Such a process implies, therefore, that social order is impermanent and requires continual maintenance through the meaning-making processes of social interaction. (For good summaries and analyses, see Meltzer 1975, Plummer 1991, and Strauss 1956 and readings in Manis and Meltzer 1967 and Stone and Farberman 1970).

5 Ethnomethodology encompasses a theory of and a method for investigating people's everyday, common sense, meaning-making activities and, more broadly, for investigating the common sense basis of social reality. It is a study of everyday life and

concerns the common sense everyday knowledge and activities of ordinary people as they make accountable to themselves and others their everyday affairs and the methods that they use to produce and manage these same affairs. It focuses on the processes of people's meaning-making activities and presents itself, in Psathas' (1980:16) words as a "reflexive social practice, which seeks to explicate the methods of all social practices including its own."

Ethnomethodology argues that the creation and affirmation of meaning and social reality are neither a priori nor automatic; Rather, the creation and affirmation of meaning and reality are viewed as being creative, open-ended, constructed, and ad hoc human endeavors.

The principle aims of ethnomethodology are to discover the methods that people use in their everyday lives to construct social reality and discover the nature of the realities they have constructed (Psathas 1968). In a narrower sense, ethnomethodology also aims to discover the "standardized and standardizing," "seen but unnoticed" background expectancies underlying people's everyday knowledge of social reality as a means of focusing on how meanings are constructed and how reality is created (Garfinkel 1964, 1967; see also Denzin 1969).

6 Garfinkel's (1967) study of how jurors decide the correctness of a verdict, for example, suggested that being a juror involved managing ambiguity more than being judicious. It involved, for example, the sorting of claims, the coming to agreement among jurors and in the end, the production of a "corpus of knowledge". Ethnomethodological studies of decision making have also shed light on the assumptions that underlie people's everyday common sense taken-for-granted understandings of reality. In his discussion of Agnes, a hermaphrodite, for example, Garfinkel (1967) shed light on the common sense assumptions underlying people's understanding of gender. My previous research on the construction of noncompliant patients (Fineman 1991a), for example, shed light on the common sense moral criteria used by health and social service providers to understand and manage noncompliance.

7 Phenomenological research of the experience of illness focuses on a number of topics including: (1) description of how people experience and manage illness (see, for example, Conrad and Schneider 1983; Mitteness 1987); (2) description and comparison of the different ways in which patients and health professionals conceptualize illness and treatment (see, for example, Gadow 1982; Kaufman 1987, 1988); and (3) description of the effects of illness, especially chronic illness, on conceptions of self and identity (see, for example, Conrad 1987b; Kastenbaum 1981; Roth and Conrad 1987).

Phenomenologically centered research suggests that chronic illness is an existentially transformative experience. Bury (1982) for example, describes chronic illness as a "biographical disruption" which necessitates a rethinking of biography and self-concept. Williams (1984) argues that onset of chronic illness requires a "narrative reconstruction of one's life." Corbin and Strauss (1987) discuss how "biographical work is a strategy for managing chronic illness. Charmaz (1987) describes how "loss of self" can be a fundamental form of suffering among chronically ill persons.

8 Issues of embodiment are central to phenomenological understandings of being. As Merleau-Ponty (1965) pointed out, the body plays a critical role of bringing existence into fruition. It is through the body that individuals receive and communicate with the world. Phenomenological studies of embodiment investigate the subjective meanings of the body. They understand the body as a lived experience and focus upon individual subjective meanings of the body (Scheper-Hughes and Lock 1987) especially in health and illness (see for example, Bologh 1981; Frank 1986; Gadow 1982).

9 For the most part, this research has focused on investigation of people's subjective meanings of age and the relevance of these meanings to identity and selfhood (see, for example, Ainley and Redfoot 1982; Esposito 1987; Gadow 1983; Hennessey 1989; Kaufman 1986; Starr 1983). Three of these studies (Esposito 1987; Hennessy 1989; Kaufman 1986) suggest that aging in American society, like disease, is experienced as an existentially transformative experience in which elderly people experience senescence as an accelerating loss of control or ownership of their corporeal bodies.

Using data from this dissertation project, I have previously reported on doctors' and nurses' subjective understandings of old age (Fineman 1994; see appendix IV).

10 Aspects of interaction were first measured by Balint 1964, a classic description of the importance of the emotional interaction between doctors and patients and how "transference' and "countertransference" influence the course and outcome of cases. Other typical studies that measure interaction include Hall et al. 1981, which found that patients want doctors to be "nice" but "serious"; Rowland-Morin and Carroll 1990, which studied the relationship between verbal style of physician and patient and patient satisfaction, and Larsen and Smith 1981, which examined the relationship between body language such as touching, physical distance, forward lean, and body orientation and patient satisfaction.

11 Hooper et al. 1982, for example, examined the relationship between patients' age, ethnicity, gender, and appearance, and physicians' interactions in terms of interviewing, nonverbal attention, courtesy, information giving, and empathy; See Beisecker and Beisecker 1990 for a study that examined the relationship between patients' social class and their desire for information. See Greene et al. 1989; Haug 1987 for studies of interactions with elderly patients.

12 "Interactional success" and "quality" in health care in these studies is typically measured in terms of standard biomedically defined parameters such as compliance (Becker M.H. 1985; Davis 1971; Ley 1988; Ley et al. 1973); recall of information (Ley et al. 1973; Unger 1995); level of patient knowledge (Bain 1976); level of patient understanding of the medical problem and physician information (Larsen and Smith 1981); and patient satisfaction (Davis 1971; Hall et al. 1988; Stiles et al. 1979).

13 Greene 1987, for example, used level of reciprocal interaction and provider enthusiasm, listening ability, information sharing, and use of technical jargon as independent variables.

14 Over the years, a number of different coding systems have been developed to analyze utterances in provider-patient interactions. The first, Bales Category Analysis (Bales 1950), for example, codes utterances in terms of 12 mutually exclusive categories of affect in communication, interaction, and decision making, such as "positive affect in question," neutral affect in response," (see Davis 1971; Korsch et al. 1968 for use of this coding method). Other systems of coding interaction have been devised by Stiles et al. (1979) and Roter (1977). Stiles et al.'s Verbal Response Mode (VRM) codes utterances in terms of eight categories of inferred communicative functions, which include disclosure, questioning, edification, acknowledgment, advisement, interpretation, confirmation, reflection. Roter (1977) developed a system modifying Bales (1950) that can code verbatim statements and indicate when statements take place. These are coded into content and affect categories such as "doctor gives orientation" and "patient show antagonism."

15 Findings of Type I studies suggest a laundry list of physician-caused impediments to successful interaction, among them: interrupting patients frequently (Beckman and Frankel 1984); not using nonverbal cues (Larsen and Smith 1981); and not providing patients with adequate information about the causes and expected courses of illnesses, or about medications (Stiles et al. 1979; Larsson et al. 1987). In addition, these studies suggest a number of physician strategies for increasing compliance and satisfaction. Some of these include increasing the amount of communication during the interaction (Hall et al. 1988); encouraging reciprocity in information giving (Roter and Hall 1989); using similar words as patients and minimizing interruptions or allowing patients to also interrupt (Rowland-Morin and Conrad 1990); utilizing social talk, using less negative talk, and trying to build a partnership with patients; using nonverbal behaviors such as physical proximity, touch, forward lean, relaxed posture, body orientation (Larsen and Smith 1981); demonstrating empathy (Goldberg et al. 1980) and courtesy (Hooper et al. 1982); requesting patient feedback (Bertrakis 1977); using short opening and concluding statements, elicitation techniques, and requests for patient feedback (Bertrakis 1977); and recognizing that information giving can reduce pain and speed recovery (Tuckett and Williams 1984); but paradoxically, that patients, when they are very sick, may actually desire a paternalistic relationship (Ende□□ et al. 1989).

16 Coser (1962) reported that if patients seek out provider sympathy, they oftentimes neither want to receive information from or supply information to providers.

17 Waitzkin (1984) found in contrast that social class is unrelated to patients' desire for information. Patients with little education, however, ask few questions.

18 Lock et al. (1989) found that 80 percent of renal transplant patients wanted more information than they were given about dialysis and transplantation, and that patients with successful transplants are more satisfied with the amount of information provided than those with failed transplants

19 See, for example, DiMatteo et al. 1993; Eraker et al. 1984; Haynes et al. 1979; Hesszen-Klemens 1987.

20 In previous research (Fineman 1991a), I described how staff members of a multiservice senior health care and social service agency perceived and managed noncompliance, a special category of difficult patients. This study was conducted between January and June, 1989 in a small urban multiservice senior agency. A representative sample of twelve staff members (clinicians, case managers, and alcohol counselors representing half of the total staff) were each interviewed for approximately four to five hours over a three month period. These interviews were structured and semi-directed. Informants were asked to talk at length about what noncompliance meant to them and to discuss the ways in which they managed their noncompliant clients.

This research led to four findings: First, staff members of this agency subjectively defined noncompliant behaviors broadly and variously as deviations from their expectations of appropriate, proper and reasonable client behavior. All staff members defined noncompliance to mean nonadherence to medical advice. But in addition, they defined it to include a host of other perceived client misbehaviors which included dishonesty, lack of cooperation, unreasonableness, irresponsibility, lack of self-awareness, closed-mindedness, lack of support for staff's efforts, tardiness, lack of self-interest, disrespect, abusiveness, and rudeness. In short, they defined noncompliant clients as being difficult.

Second, staff members interpreted the meanings of clients' noncompliance by subjectively assessing the intent underlying their clients' noncompliant behaviors. In doing so, they constructed an elaborate typology that distinguished between clients who were perceived to be unwilling to comply and those who were perceived to be unable to comply. The category of unable comprised those noncompliant clients who were deemed by staff to be: (a) "demented", (b) "disabled", or (c) "alcohol addicted". The category of unwilling comprised those noncompliant clients who were deemed to be: (a) "manipulative" or (b) "recalcitrant", "rigid", or "stubborn". Typically, manipulators were defined as clients who "sabotaged" agreements or "worked the system" by doctor shopping, provoking fights among staff members, or seeking undeserved services.

Third, staff assessments of clients' willingness and ability to comply functioned in three important ways: (a) They served as a means of making their clients' perceived misbehaviors meaningful to them. Staff members interpreted the noncompliance of unwilling clients as acts of deliberate and calculated misbehavior, defiance and deviance. Unwilling clients, in essence, were seen as moral transgressors and were labeled as being bad. In contrast, staff members interpreted the noncompliance of unable clients as manifestations of illness or incompetence. Unable clients were thus viewed as hapless victims. Though troublesome, their noncompliant behaviors were perceived to be unintentional and blameless. (b) Staff's assessments functioned to assign blame to noncompliant clients. Unwilling clients were blamed for their noncompliance; Unable clients were not. (c) Staff's assessments functioned to allocate responsibility for clients' future care. Staff members assumed only limited and tenuous responsibility for the care of those they perceived as being defiant and undeserving. However, staff assumed complete responsibility for the future care of those they perceived as Unable and therefore sick.

Fourth, staff members' assessments of clients' ability or willingness to comply served to structure their subsequent interactions with clients and provided the rational and moral bases for the strategies that staff used to manage clients' noncompliant behaviors and bring about compliance. Clients who were perceived to be unwilling to comply were managed by use of two strategies of punishment. These included: (a) confrontation; and (b) renegotiation of client contacts with more stringent or explicit conditions of compliance. Clients who were perceived as unable to comply were managed by use of three alternative strategies of control. These included: (a) reassessment of patient/client needs; (b) control of clients' physical environments; and (c) renegotiation of client contracts with less stringent or explicit terms.

21 Good summaries of sociolinguistic studies include Mishler (1984) and Fisher and Todd (1983). Articles in Fisher and Todd are wide-ranging and focus on the interrelatedness of language and social context in medical encounters (where context is defined to range from level of interaction between doctors and patients to the organization of medicine and of society). Mishler (1984), is a comprehensive and critical review of previous research on doctor-patient interaction that focuses on the analysis of transcripts of medical interviews in an effort to interpret the structure and content of medical interaction. He places the talk in the larger contexts of different world views of patients and providers, and finds that doctor-patient talk represents two views of the world, which he depicts as the doctor's "voice of medicine" and the patient's "voice of the lifeworld."

22 Heath (1984) has shown that medical encounters, like other forms of social interaction, require that participants cooperate to sustain some semblance of mutual involvement in the interaction, and thereby coordinate their actions and activities. For example, he shows how doctors and patients coordinate verbal and nonverbal behaviors by using gestural activity to realign the gaze of recipients and encourage participation in talk. This body of research has also focused on the ways in which doctor-patient interactions break down, and the kinds of everyday repairs that are used to mend communication difficulties. For example, Robins and Wolf (1988) discussed how

medical students, faced with a patient's noncompliance, used confrontation and politeness strategies to preserve face and repair conversational breakdown.

23 Fisher (1984) has observed broadly that although doctors and patients negotiate medical decision making, these negotiations are heavily weighed in doctors' favor. Mathews (1983) suggests the reason for this is that physicians assign patient roles rather than allowing them to choose roles for themselves. Cicourel (1981) observed that face work and interaction conduct rules are frequently rescinded in clinical settings. Specifically, he noted that physicians inform patient inquiries with a variety of cues to shut them down including: continuing to talk and not paying attention to patients' input; shifting topics to avoid sensitive topics; using technical jargon; and using nonverbal cues such as walking away without answering, limiting time, and maintaining spatial distance. Similarly, many authors including Coulthard and Ashby (1975); Frankel (1983a); Mishler (1984); Platt and McMath (1979); and Waitzkin (1984) have noted that doctors often maintain a style of high control that involves many doctor-initiated questions, especially closed-ended questions, interruptions, and neglect of patients' life world. In more recent work that uses a narrative analysis drawing on literary criticism and critical theory, Waitzkin and Britt (1993) examined medical encounters to assess how patients and doctors communicate about the difficult topic of patients' self-destructive behaviors such as smoking and substance abuse. They found that the discourse of health care reinforces ideological principle of surveillance and individual control in dealing with patients' self-destructive tendencies, and that contextual issues remain largely marginal features of the discourse.

CHAPTER 3

METHODS

Overview

This dissertation asks how health care providers create understandable meanings of difficult patients, and what those meanings are. In order to answer these questions, the study principally uses standard ethnographic procedures that enable "thick description" (Geertz 1973). The study is defined by three essential dimensions of qualitative research: it is holistic, inductive, and naturalistic (see Guba and Lincoln 1995; Marshall and Rossman 1989; Patton 1980) and is guided as well by a commitment to humanism (see Schatzman and Strauss 1973:4-5).

Methods for this dissertation followed guidelines suggested by Blumer (1969), Guba and Lincoln 1981; Lincoln and Guba 1985; Miles and Huberman (1994), and Strauss (1987) for conducting intensive, empirically grounded, naturalistic field research. Specifically, procedures used here to collect, code, and analyze data were inductive, pragmatic, synthetic, and orderly.[1] These procedures were designed with three objectives: (1) to develop a close and full familiarity with the physicians, nurses and patients under study; (2) to develop and shape inquiry so that problems, directions of inquiry, data, and interpretations of data were empirically grounded; and (3) to utilize explicit and operational tactics in order to draw and verify meanings from qualitative data and lead to maximal understanding (Verstehen). Data derived from in-depth interviews with physicians, nurses, and patients, long-term observations of three clinical settings, and inspection of medical records for building illustrative case studies.

The study combines an interpretivist/constructivist stance with the judicious use of explicit and rigorous methods. These perhaps conflicting positions raise the paradox recognized by Schwandt (1994) of developing objective methods to interpret subjective human experience. Following a description by Schwandt (1994), I take a "middle-ground" position that presumes that while there may be no single reality to discover, no single reality that is “right,” there is nonetheless "permanence and priority" to the real world of first-person, subjective experience, the details, complexity, and situated meanings of which are interpretable through a variety of methods. Following the suggestions of many methodologists (Guba 1981; Miles and Huberman 1994) I hold that there are operational guidelines for defining a problem, and for sampling, collecting, reducing, and analyzing data, that assess and judge the thoroughness, coherence, and comprehensiveness of an account of subjective experience. I was also mindful of the design considerations recommended by Lincoln and Guba (1985) for fitting together the purpose, approach, and theory underlying the research.[2] The aim of this chapter is to describe explicitly the procedures I used to collect manipulate, and analyze data to draw the conclusions made.

The chapter begins with a description of the field site, which includes descriptions of the hospital and the three clinical research settings, and description of hospital staff members and patients. Following these, it then describes in detail the sources of data, and the procedures used to collect, code, and analyze data. Finally it briefly discusses relevant methodological issues of this project including gaining entry and rapport, defining generalizability, validity, and reliability.

Description of Field Site

Mt. Sinai Hospital

Mt. Sinai Hospital (a pseudonym) is a 300-bed community teaching hospital in a large western city. The hospital, which was founded in 1892, has a long-standing commitment to community health education, social service, and activism. The hospital's mission statement reads in part that it is "committed to excellence and to the traditional Jewish values of charity, education, and the pursuit of knowledge" in order to provide "relevant, high quality, and efficient hospital care to the community at large." Although the original mission of the institution was to serve the predominantly Jewish (and poor) residents of the surrounding community, as the demographics of the area changed, this mission was broadened to include other community groups as well. Today, the hospital serves mainly a large, poor and working-class African American population that moved into the area during and after World War II. Under contract with Jewish Family Services, it also provides health care for a large and growing population of newly arrived (and mostly

Jewish) Russian émigrés. Because donations from the Jewish community and monies from the Jewish Community Federation underwrite their care, Jewish patients receive special perquisites, and certain eligibility requirements for them are waived. For example, all Jewish patients (including Israeli students residing in surrounding counties) regardless of their financial circumstances are eligible for outpatient care. In addition, Jewish patients receive care for lower fees than other patients. At the time of the fieldwork for this dissertation, many long-time staff members feared that the hospital's traditional commitment to serving uninsured and indigent members of the local community was in jeopardy as a consequence of the hospital being absorbed into the network of a large and bureaucratic university hospital system.

Mt. Sinai provided care for both private patients (patients who were attended by private physicians and who generally had some kind of health insurance) and nonprivate or "clinic" patients (patients who were without a private attending physician and who very often had no health insurance). In terms of the organization and provision of care the hospital made no distinction between the two categories . Indeed, its "Rules and Regulations" recognized the educational value of serving both private and nonprivate patients:

> We feel that the presence of both categories of patients on the teaching services enhances the residents' educational experience since they learn to communicate and interact in a favorable manner with other physicians outside their immediate sphere. Moreover, the presence on the teaching services of patients from often very different socioeconomic and cultural backgrounds, in addition to widening the spectrum

> of disease encountered, contributes to the residents' overall educational experience. [Medical Rules and Regulations, p. 155]

Mt. Sinai hospital is housed in a modern seven-story main building and a few adjacent older buildings. The hospital contains an Emergency Department (ER) that provides 24-hour nursing and physician care for walk-in and ambulance patients for urgent and emergent medical problems; a Critical Care Unit (CCU) that provides both intensive treatment and intensive monitoring; a Home Care Program to provide ongoing medical, nursing, social service, and rehabilitation services to homebound patients; an Institute for acute rehabilitation services; a Skilled Nursing Facility (SNF) that provides transitional, subacute care (for 10-20 days) for patients who do not meet the criteria for acute hospitalization, but who are still too ill to be sent home; a Tumor Institute and Tumor Board, a multimodality cancer treatment center that delivers patient care and that provides oncology training and cancer research; and Departments of Anesthesiology, Dentistry, Dermatology, Family Practice, Medicine, Neuroscience, Obstetrics and Gynecology, Opthamology, Orthopedic Surgery, Otolaryngology, Head and Neck Surgery, Pathology and Laboratory Medicine, Pediatrics, Psychiatry, Radiation Oncology, Radiology, Surgery, and Urology.

The Department of Medicine contains nine subspecialty divisions including cardiology, which provides laboratories and electrocardiography; diabetes and endocrinology, which is responsible for the diabetes and endocrine research laboratory; gastroenterology, which is responsible for the endoscopy unit and nutritional support services, geriatrics, which is responsible for all geriatric services, for the skilled nursing facility, for liaison with the nearby Jewish Home for the Aged, and also is the medical component of a separate but allied geriatric and gerontology research and educational facility; infectious diseases, which is responsible for the microbiology and virology laboratories; oncology, which is responsible for the oncology care unit; nephrology, which is responsible for the dialysis unit; physical medicine and rehabilitation, which is responsible for the rehabilitation unit; and pulmonary medicine, which is responsible for the pulmonary function lab, respiratory therapy, and the critical care unit.

The Teaching Services

Mt. Sinai is a teaching hospital, meaning that a good deal of the care provided is organized through the teaching services of the intern/residency program. Nonprivate patients were automatically admitted to the teaching services, under the care of an assigned faculty-practice physician. Private patients and private attending physicians had the prerogative of selecting between the teaching and nonteaching services. When placed on the teaching service, private patients were attended by their private physicians in concert with house staff residents and interns.

There were five general medicine teaching services, each comprising approximately 12 to 15 patients. Each of the teaching services was staffed by one medical resident, one intern, one fourth-year medical student, one third-year medical student, and sometimes a pharmacy student.

The teaching services were actively supported by a system of teaching and patient management rounds, and by medical consultations with faculty-practice (and sometimes private-practice attending) physicians. Although these management and teaching rounds were distinct activities, their functions often overlapped: Management rounds had definite educational value and work rounds not infrequently contributed to patient management and care.

Management (Work) rounds. Management rounds took the form of bedside work rounds during which residents and their teams visited with each of the patients on their service every morning including weekends from 8:00 - 9:30 A. M. The function of these rounds was for all house staff to review the medical status of each patient for whom they were responsible. These rounds consisted of a brief presentation of each case by an intern or fourth-year medical student to the resident, a bedside visit with the patient, and a concluding assessment of the patient's medical status and treatment plan. Case presentations were short summary statements of the case the team was about to visit and included (ideally) a one- or two-sentence statement of the patient's history, an explanation of the differential diagnosis, mention of any special anomalies, and a summary of the patient's present condition and treatment plan.[3] Special management problems were brought to the attention of the Chief of Medicine at daily residents' report, to the attention of the private attending physician in the case of a private patient, and to the attending faculty-practice physician in the case of a nonprivate patient.

Residents' reports. Residents' reports were structured didactic conferences held daily with all residents and the chief of medicine or an assigned replacement. Each day a different resident was assigned to present a special medical topic for discussion. Residents rarely missed these meetings and planned their presentations carefully. They took great pleasure when a patient on their service could serve as a case study of an important medical lesson in diagnosis, treatment, or management. Such patients were by residents' own descriptions often defined as "difficult." These sessions also served as an informal social hour during which residents could interact collegially with one another.

Attending rounds. Teaching (or attending) rounds took place daily from 11:00 am to 12:00 noon. On Mondays, Tuesdays, Wednesdays, and Thursdays, teaching rounds were conducted by the teaching attending physician assigned to the service for the month. On Fridays, teaching rounds were conducted by the Chief of Medicine. During attending rounds, all patients were reviewed a second time by the team--but this time with the attending present. Teaching rounds generally took the form of one or two case presentations by the intern, followed by an in-depth discussion of each patient's differential diagnosis and management.

Grand rounds. Grand rounds were a formal and traditional ritual that attendings, house staff, and students were expected to attend. They consisted of a formal presentations of a single case of particular medical interest in the hospital lecture hall by a respected physician. Medical Grand Rounds took place in the hospital lecture hall once a week on Fridays.

Staff Members: Roles and Responsibilities

This section briefly describes hospital staff members' normative roles and responsibilities as described by hospital administrators and in hospital manuals of policies and procedures. In the everyday world of medical practice however, roles, and responsibilities among attendings, residents, and interns were actually more complex than these descriptions might suggest. Indeed, depending on individual differences in providers' medical specialties, differences in individual practitioners' perceptions of their roles and responsibilities, and differences in individual temperament and management style, the distinctions in providers' roles and responsibilities noted here were often blurred, and were sometimes also a source of patient difficulty. (Mizrahi 1986 and Mumford 1970 make essentially the same point.)

Attendings. *Attending physician* is the title given to those medical directors, faculty practice physicians, and physicians in private practice who have assigned patient care responsibilities. *Faculty practice attendings* were formal members of the hospital's management and teaching team who, in addition to having patient care responsibilities, also had assignments in teaching, research, or administration. Faculty practice attendings, though the titular heads of the patient care teams, shared administrative responsibility for patients with the residents. It was estimated that about 160 private and faculty-practice physicians attended patients at Mt. Sinai.

Residents. Residents supervised and managed the teaching services and were directly involved in the total care and management of all patients on the teaching services. They supervised the interns, and taught the medical students. Among teaching-service patients, residents had the final authority to accept, reject, discharge, or transfer patients. They also made the major therapeutic and medical management decisions. However, it was not their structured role to always be directly available to patients. This job fell to interns. During the time of my fieldwork, there were 12 residents at Mt. Sinai.

Interns. Interns implemented the decisions of residents. In the words of Mizrahi (1986) and Bosk (1979) they did the "scut work" of medical management. Interns were responsible for carrying out the day-to-day decisions made for each patient and for handling most patients' management problems, performing all the services a patient needed, whether or not those services were part of their official job title. In short, they were responsible for everything, but had little authority.

Interns were traditionally overworked nearly to the point of physical and mental exhaustion. It was common for them to be in the hospital between 80 and 100 hours a week. Even if they were not on call, their days began early, usually around 7 A.M., and often lasted well into the evening. Interns often seemed chronically fatigued, harassed, inundated, and fed up with the pace and stress of their schedule. Attendings, residents, nurses, social workers, the laboratory, patients' families as well as patients themselves clamored for their attention. The pace was frenetic. They ran from appointment to appointment. Their pagers were constantly beeping. A few used moderate amounts of amphetamines to stay awake and alert.

Because of the long hours they worked, their professional zeal, and the circumstance that many of them were new to the area and had few if any personal relationships outside the hospital, house staff interns were a close and supportive group. Mizrahi (1986), too, noted the solidarity among interns and suggests that as a group house staff owed their allegiance and accountability to each other and their residents, to whom they looked for training, approval, and support). There were 14 interns at Mt. Sinai.

Medical students. Third- and fourth-year medical students also rotated through the teaching services and were assigned to a team. But they did not have any official patient management authority. Hence, theirs was more a learning than a service role.

RNs (registered nurses) Registered nurses were primarily responsible for providing and supervising day-to-day nursing care of patients, keeping patients medically stable, and carrying out doctors' orders. At Mt. Sinai, most RNs had 4-year nursing degrees, and to keep them abreast of current knowledge, also had continuing education credits, a state requirement for maintaining certification. RNs on 7E and in the rehabilitation unit worked independently with minimal clinical supervision. Nurses in the clinic reported to the charge nurse. With some additional training, many RNs also performed a number of nonclinical functions as described below.

RN/specialists. RNs, often without any formal accreditation process, performed specific nonclinical duties in the hospital including utilization review, discharge planning, and social work. Utilization reviewers worked directly with nursing staff, social workers, and doctors to monitor patients' length of stay, facilitate quality of patient care (for example, by checking that attending physicians saw patients every day and by recommending the need for specialist consults when necessary), and to expedite discharge. Their primary responsibility was to bring uniformity and cost reduction to patient management. In most cases, they had little or no direct contact with patients; As they themselves explained it: "We only read the charts." RN/discharge planners (and often social workers, too) planned strategies of patients' posthospitalization management. They made specific arrangements, for example, for patients' placement (to home, a SNF, a board and care, etc.) after patients left the hospital. In addition, they dealt with issues of death and dying with patients and their families. RN/social workers also did discharge planning but dealt with patients' psychosocial needs as well.

LVNs (licensed vocational nurses) LVNs, like clinical RNs, administered patient care. They performed essentially the same clinical jobs as RNs, for example, changing dressings and entering notes into medical records. However, unlike RNs they were not considered to have primary responsibility for patients or leadership responsibilities. They could not, like RNs, sign off orders in medical records. Nor could they put IV lines into patients or administer medications through IV lines. These limitations rendered them dependent on supervision by RNs, a circumstance that a few LVNs resented.

The Three Research Settings

The multiple clinical settings at Mt. Sinai provided a virtual laboratory for the exploration of provider/patient interactions. The research for this project was largely conducted in three different clinical settings: the general medicine outpatient clinic; an acute care general medicine inpatient unit; and the acute care inpatient rehabilitation unit. These sites were chosen for three reasons: (1) they offered a convenient way to compare the ways in which providers perceive difficult patients in a variety of different clinical settings; (2) they provided access to a large number of physicians and nurses, and (3) they provided access to a large number of patients.

The General Medicine Outpatient Clinic. The Outpatient Department of Mt. Sinai provided a full range of outpatient services in Medicine (general, geriatric, and subspecialties of cardiology, endocrinology, hematology, infectious diseases, nephrology, neurology, rheumatology, and psychiatry), Surgery (general, urology, otorhinolaryngology, orthopedics) Ophthalmology, Gynecology, Psychiatry, Pediatrics, Dermatology, and Neurology.

Fieldwork for this project focused primarily on study of the general medicine clinic of the Outpatient Department. This was by far the busiest of all the outpatient clinics. The clinic was open daily between 9:00 A.M. and 4:00 P.M., and saw between 50 and 60 scheduled and walk-in patients a day. Appointments were usually booked two weeks in advance.

The clinic was small and usually bustling. The waiting room, which seated about 20 people, was often quite noisy and crowded with few if any empty chairs available. There was often a din of ringing phones and chattering patients and families, doctors, nurses, and Russian translators. Patients often waited as much as two hours before being seen by a doctor. (Medical and clerical staff said this was due to the fact that Russian patients, hoping to be seen before their scheduled appointment times, arrived extremely early for appointments. Russians patients said that they just wanted to make sure that they were not going to be overlooked.) The clinic contained a waiting room, eight examination rooms, and a tiny conference room that interns and residents used for writing up medical orders, conferring with each other about cases, making and taking phone calls, and socializing informally with one another (see Figure 3:1).

Clinic staffing. The clinic was usually staffed by eight or nine doctors, a charge nurse and LVN, two clerks and a clerical volunteer, and four or five Russian translators. Medical staff included a full-time salaried medical director (who was a senior member of the Department of Medicine); an assistant medical director, (also a salaried member of the Department of Medicine), who was directly responsible for supervising and teaching ambulatory medicine to residents, interns, and medical students; a teaching attending physician assigned by the Chief of Medicine; residents; interns; and medical students.

Care in the medicine clinic was largely provided by the staff of interns and residents. Residents served as the primary consultants to interns and as medical consultants to the other outpatient subspecialty clinics. They were also responsible for triaging patients with the charge nurse, refilling prescriptions, and seeing overflow patients when interns were unable to do so. When outpatients required admission to the hospital, final evaluation and disposition of these patients was the responsibility of the medical resident in conjunction with the Chief Medical Resident and, if necessary, the Assistant Director.

Residents were also responsible for following their own group of patients. Each resident typically spent one-half day per week in the clinic throughout his or her three years of training and saw on the average of five follow-up patients and one new patient per week. Residents thus maintained an ongoing practice of clinic patients to which new patients were added throughout their residencies. They and they alone were responsible for the ongoing care of these patients and for initiating appropriate follow-up treatments.

In addition, each resident was assigned to two or three one-month block rotations during each year of residency. During these rotations, they worked as head of a team consisting of three interns and two fourth-year medical students that was responsible for the care of new patients, drop-in patients, and patients who had no long-term physician or who had not previously been assigned to a resident. Medical residents were also responsible for general medical consultations on nonprivate patients requested by other disciplines during the day. The Chief Resident supervised this activity.

Interns handled all new patients. They did initial patient histories and physical examinations, initiated patient care, and were responsible for all patient charting and documentation. Each intern saw about 12 patients per day. Interns were required to present all patients to the resident and to the Assistant Director, Director, or teaching attending physician. Attendings were required to countersign all interns' notes and prescriptions.

Nursing responsibilities in the outpatient clinic included triaging and screening patients, taking weight and blood pressure, giving injections, coordinating the flow of medical records, and screening medically related phone calls to the clinic.

Interns and residents were of two minds about working in the clinic. Some (especially those who were going to specialize in the generalist subspecialties such as internal medicine, family practice, or pediatrics, often enjoyed the time spent in clinic and liked the interaction with patients. Others (for example oncology specialists) often resented the time spent in clinic and viewed their work there as interrupting their inpatient responsibilities, which they perceived as more important.

Description of 7E an Acute Care General Medicine Inpatient Unit. Seven East is a 21-bed acute care general medicine inpatient unit (Figure 3:2). The unit was divided into two sections: 7Ea was dedicated to the care of HIV/AIDS patients; 7Eb treated patients with all other acute general medicine problems. These ran the gamut from acute pulmonary problems, to sepsis, to broken bones, to heart attacks and strokes. The unit was staffed during the day by a nursing director, two assistant nursing directors, five RNs, seven LVNs, a social worker, a utilization reviewer, and a public health nurse. Seven East was a central location of the general medicine teaching services. All teaching-service teams met here every morning at 7:30 A.M. for work rounds.

7 East staffing. Mt. Sinai maintained the traditional chain of responsibility from intern through medical resident to attending physician. Attending physicians, though retaining ultimate responsibility for patients' care, delegated day-to-day management of patients to residents. Residents supervised the interns and students, assumed primary responsibility for all aspects of the care of the patients on the service, and maintained communications with the private attending or faculty practice physician and the Chief of Medicine. After completing initial work-ups, residents were responsible for promptly notifying private- and faculty-practice attending physicians about any changes in patients' condition, and for securing permission to undertake any major tests, procedures, or radical changes of therapy.

Interns were responsible for doing complete histories and physical examinations of new patients on admission and were responsible as well for initiating and organizing various aspects of the diagnostic work on new patients. Diagnostic work consisted mostly of ordering, overseeing, and conducting procedures, and was always performed in consultation with a resident. These tasks comprised a major part of their work load and included deciding what tests to conduct; ordering the tests or procedures; transporting patients to the testing sites; witnessing, assisting, or performing the tests; retrieving, interpreting and discussing the findings with residents; and entering the results and interpretation into the computer and medical record. They also charted admission work-ups and progress notes.

In addition, interns on 7E were responsible for examining the ongoing patients on their service every day, seeing that orders were carried out correctly, that patient management decisions were medically effective, and that patients were appropriately discharged or transferred to other care settings. They also prepared discharge summaries on both private and nonprivate patients.

Admission and discharge of patients. Patients were admitted to the unit from home, from the hospital ER and CCU, and from other care institutions, either a SNF, a board and care, or another hospital. Admissions of private patients were typically authorized by a private attending physician, or if through the ER, by ER staff in consultation with an assigned faculty practice physician and with the resident on the admitting inpatient service; admissions of nonprivate patients were authorized by a resident or faculty attending physician in the ER. For teaching service patients, medical residents on the admitting inpatient service assisted in the evaluation and triage of the patient, and maintained open lines of communication with the assigned faculty practice or private attending physician. All admissions were coordinated directly with the director or an assistant director of nursing.

Private attending physicians were responsible for discharging nonteaching-service private patients on 7E; In consultation with the teaching-service resident, faculty-practice physicians were responsible for discharging teaching-service patients. Discharges were also coordinated with the nursing department, utilization review, and if necessary, the home health care nurse.

Nursing Rounds. Nursing rounds differed in structure and purpose from medical work rounds. In contrast to medical work rounds, which focused almost exclusively on issues of disease management, nursing rounds tended to focus more broadly on issues of patients' total care management. These issues included keeping patients medically stable, but also focused on issues of patients' behavior, social problems, and discharge plans. Nursing rounds on 7E were conducted once a week on Tuesday mornings in a small nursing office conference room. Rounds were attended by the Nursing Director, an Assistant Nursing Director, the unit social worker, and the unit utilization reviewer. Patients were presented in turn by the RN or LVN assigned to each one. These presentations consisted of brief descriptions of patients' present status, special nursing or medical problems, and medical prognosis. Following these initial presentations, discussion focused specifically on issues of discharge and disposition, during which the nursing supervisor, utilization reviewer, and social worker arrived at a mutually agreed upon disposition plan.

Description of rehabilitation unit. The Rehabilitation Unit of Mt. Sinai Hospital is a 34-bed inpatient unit that provided comprehensive, coordinated rehabilitation services including 24-hour nursing care, rehabilitation nursing, physical therapy, occupational therapy, speech therapy, social services, psychological services and vocational services (see Figure 3:3). At the time of my field work, utilization of the unit was at an all-time low. There were on average only about 10 patients on the unit. The low census was the result of two factors: (a) a recent and sharp decline in the number of diagnoses eligible for paid rehabilitation under new private insurance, Medicare, and Medicaid regulations; and (b). decrease in the number of paid days of rehabilitation for those diagnoses that were still deemed eligible for reimbursement. Only

21 beds were currently in use. The remaining unused bed space had been converted into administrative offices for the Medical Director, and directors of the physical therapy (PT), occupational therapy (OT), and speech therapy (SP) staff, a conference room, and a lunch room. Staff members feared that the incorporation of Mt. Sinai into the university hospital system was likely to speed the process of down-sizing (or even eliminating) the rehabilitation unit. They believed that the university's medical directors did not support rehabilitation therapy as a legitimate medical endeavor, a belief that was probably not unreasonable given that the university hospital did not even offer inpatient rehabilitation services.

Rehabilitation unit staff members. Staff on the unit included a medical director, directors of physical, occupational, and speech therapy, physical, occupational, and speech therapists (most of whom were on-call registry employees), three RNs and four LVNs, a social worker, and administrative and clerical personnel. The medical director, a physiatrist (a physician specializing in physical medicine, i.e. physical therapy), was responsible for the medical direction of the unit, a primary task of which included determining whether or not a patient was likely to benefit from care on the unit.

Patients' progress was assessed weekly in case conferences. Staff members on the unit were divided into three teams, each of which was composed of nurses, physical therapists, occupational therapists, and speech therapists. Each team reported on their patients once a week in case conferences. These conferences were attended by the medical director, the social worker, a nurse, and a representative of each of the three therapy modalities. Case conferences lasted about an hour and typically discussed in detail the status, progress, and prognosis of three to four patients.

The rehabilitation unit was not part of the hospital teaching services. As a consequence interns and residents rarely visited the unit. Private patients were attended by private physicians. Nonprivate patients were attended by the unit's medical director. A practical consequence of the lack of house staff physicians on the floor was that the rehabilitation unit was looked on with some scorn. Most house staff physicians did not think of rehabilitation as medicine at all.

Admission to the unit. Patients were admitted to the rehabilitation unit either directly from the outside or as transfers from other units in the hospital, in particular, the hospital SNF. The primary requirement for admission to the unit was patient need of intensive intervention of at least two rehabilitation modalities, and the ability to sustain a coordinated program of increasing activity and increasing independence in self-care. Physical therapy was provided only to those patients that demonstrated rehabilitation potential. Preadmission screening included a medical review, an evaluation of patients' rehabilitation potential, and a review of future placement resources. A treatment plan was developed for all patients based on an evaluation of their functional abilities.

Length of stay on the unit was determined by patients' rehabilitation potential and the speed with which they progressed. It varied from several days to several weeks, and in rare cases, extended to several months. The average stay was between 17 and 21 days. Patients' progress was reviewed in weekly interdisciplinary rounds at which time the treatments plans and goals were reevaluated. Patients and their families participated "as appropriate" in the development and implementation of the treatment plan.

The focus of rehabilitation treatment was to improve ADLs and IADLs.[4] Treatments included range of motion exercises, neuromuscular reeducation strengthening exercises, joint mobilization, muscle stretching, balance and coordination activities, transfer training, bed mobility, gait training and, and prosthetic training. In addition, therapists used a multitude of modalities to aid in the effectiveness of their treatments. Some of these included hot packs, ultrasound, electrical stimulation, cold pack, ultraviolet light, and intermittent traction.

Description of Patient Population

Mt. Sinai drew from a diverse urban population, but focused especially on the treatment of local community residents, most of whom were poor and working-class African Americans or Russian émigrés, and many of whom were elderly. Patient populations varied from unit to unit. The outpatient clinic population was largely Russian. The clinic director estimated that perhaps 60 percent of clinic patients were Russian émigrés.

Patients on 7E, the general medicine inpatient unit, encompassed the whole range of Mt. Sinai patients and therefore represented a broad range of ages, races, classes, and ethnicities. AIDS patients tended either to be gay, white, and middle-aged (ages 30 to 60), or heterosexual, black or Latino, and middle-aged. Patients on 7Eb the non-AIDS side of the floor, tended to be elderly and often Russian. The nursing director estimated that more than 75 percent of patients on 7Eb were 65 years or older and that perhaps one-third were Russian émigrés.

The patient profile on the rehabilitation unit was unique in the hospital. Patients on the unit were predominately elderly, female, and white. Most had been diagnosed as having had a stroke (CVA). Of 182 admissions to the unit in 1992, 70 percent were over 70 years of age, 60 percent were women, and 120, or two-thirds, were hospitalized as a the result of a CVA. Although there was no age limit for admission (ages of admissions to the unit during 1992 ranged from 23 to 101), patients under 18 were very rare. Other typical but less common admission diagnoses included hip fractures, Parkinson's Disease, multiple sclerosis, and neuropathy.

Data Collection

Fieldwork for the this study began in June, 1992 and concluded in December, 1993. Data for the study derived three sources: (a) long-term structured observations of doctors, nurses, and patients in the clinical settings described; (b) on-going informal conversations and structured interviews with doctors, nurses, and patients; and (c) inspection of patients' medical records for use in the construction of illustrative case studies.

During the field work period, I tried to immerse myself in the work; that is, I was generally at the hospital all day, four or five days a week. I used the principle of "saturation" (Glaser and Straus 1968) to decide when to stop interviewing or observing an event or series of activities. Specifically, I stopped interviewing and observing when I found no additional data for identifying or developing properties or categories, and when I found myself repeating myself in field notes.

Interviews and observations focused disproportionately on members of the house staff, with whom I spent the most time. But insofar as I could tell, their perceptions, understandings, and beliefs, about difficult patients were no different than those of attendings. This is consistent with the view of Mizrahi (1986) that doctors' lifetime perceptions of the doctor/patient interactions are forged in intern and residency training.[5]

While all members of the house staff physicians were to some extent subjects of the study, I scrutinized some more than others. Table 3.1 summarizes differences in the number of activities that I observed. As indicated, the study focused most on observing house staff physicians and nurses. Although they were often interviewed both formally and informally, private attending physicians were rarely subjects of observation. I did, however, observe about half of the private attending physicians interviewed in at least one interaction with a patient they described as difficult.

Participant-Observations

Participant-observation is a principal method of anthropological investigation and its advantages have been summarized by many researchers (see, for example, Becker 1970; Spradley 1980).[6] Structured observations of doctors' and nurses' interactions with patients and with each other at each of the three research sites were a critical part of this study. Observations began the first day of field work and continued throughout the data collection period. However, the sites and activities under observation changed over time as the aims and purposes of observations changed. Initially, I planned observations to reveal a global view of the hospital, its staff members, and its patients. This strategy was intended to provide me with opportunities to meet providers and patients informally, and thereby speed gaining entry and build rapport. Subsequent observations were increasingly topic-specific and focused upon providers' "backstage" (see Goffman 1959) interactions. Overall, I planned to continually narrow the focus of observations in order to address increasingly narrow research questions and concerns.

Initial observations: months 1 - 3. Initially, observations were global and focused upon providers' public interactions. During the first three months of field work, my observations focused on intensively examining the public areas of the three sites. These included the waiting room and registration desk in the outpatient clinic (see location A in Figure 3:1) and the hallways and nursing stations of the two inpatient units (see location A in Figures 3:2 and 3:3). These observations were highly structured and tightly bounded. Observations of these areas were made for one hour at a time, at varying times of the day, and on varying days of the week (sometimes including evenings and weekends). I made observations as unobtrusively as possible in order to allow staff members to go about their day-to-day routines with little thought of my presence. I neither tape recorded nor took notes during these observations. Detailed records of observations were tape recorded immediately following each one. Observations noted the people involved in each interaction, the activity going on, the social context of the interaction, and the emotional quality of the interaction.

Focused Observations: months 4 - 14. Observations during most of the subsequent year of field work focused on participating in and observing specific activities in each of the three clinical settings. These are summarized below in Table 3:1. In the outpatient clinic, I stationed myself in the clinic conference room, the gathering spot for physicians during periods between patient appointments, the location in which interns presented their cases to the clinic director or resident, and the place where they wrote orders. This location gave me the opportunity to listen to doctors' stories about difficult patients before or while these patients were in the clinic. It thus also gave me the opportunity to ask to observe interactions with these patients in the examination rooms.

Observations of 7E, the acute care inpatient unit, focused on doing morning work rounds and attending rounds with each of the medical teams, sitting in on residents' reports and nursing rounds, visiting patients with doctors and nurses, and hanging out at the nursing station, where staff members gathered to enter notes in patients' charts. These observations, too, were extremely important for identifying to me patients whom providers perceived to be difficult and for revealing providers' spontaneous reactions to difficult patients.

Observations of the inpatient rehabilitation unit focused on watching providers' interactions with patients during physical, occupational, and speech therapy, attending weekly case conferences with each of the rehabilitation teams, and visiting patients during daily nursing routines. Because this unit was not a part of the teaching services (with the consequence that house staff rarely visited this unit) observations of patient interactions with doctors were restricted to observations of patient interactions with a very limited number of private attending physicians and the rehabilitation director. As a result, I ended regular observations of the rehabilitation unit after month nine. However, in an effort to maintain contact with the unit and continue observations of difficult patients there, I periodically checked in with rehabilitation staff members to inquire if there were any particularly difficult patients on the floor worth following.

Final Observations: months 15-18. Observations during the last four months of field work concentrated almost exclusively on observing provider interactions with or about difficult patients in the outpatient clinic and the general medicine inpatient unit. These observations focused especially on provider interactions with patients whom providers identified as very difficult.

Table 3.1 Description of Focused Observations

Type of Observation	Number Attended
7E, 6E Work and Attending Rounds	52
Rehabilitation Rounds	27
Outpatient Clinic Patient Examinations	21
7E Nursing Rounds	19
Rehabilitation Clinic Patient Examinations	16
Residents' Reports	15
7E, 6E Patient Examinations with Attendings	11

My Roles.. Many researchers (see, for example, Bosk 1979; Mizrahi 1986) have commented on the many roles played by ethnographers doing participant-observation. Bosk (1979; see pp. 193-198 for a detailed description of his roles as "gofer," "emissary from the outside world," "fellow-suffering student," "sounding board," "referee," and "group historian."), in particular, has commented that the number and variety roles he played were instrumental in gaining him trust. And Chrisman and Johnson (1990) have noted that defining one's role is one of the special difficulties of doing field work in professional settings because everyone but the ethnographer has a very well defined role.

In truth, I did not actually play very many roles at Mt. Sinai. Like Bosk, I shared the role of student with house staff interns and residents. Because Mt. Sinai is a teaching hospital, my role as student was accepted easily by physicians at all levels, by patients, and accepted as well by nurses. But this was essentially the only role I played, although in some limited contexts I was a gofer too. Also, as an aspiring anthropologist I was viewed by some staff members as a "culture expert" and was occasionally asked by them for advice about the medical practices and beliefs of foreigners, especially Russians. For example, in one instance, I was asked by the chief of the outpatient clinic to report to the Medical Ethics Committee of the hospital why Russian patients resisted being informed about terminal cancer diagnoses.

Interviews

Interview subjects included most of the interns and residents of the house staff, a small number of faculty and private practice physicians, most of the nurses on the day shift in the three clinical settings studied, and a small number of patients whom doctors or nurses identified to me as difficult. Due to differences in the accessibility of these groups of study subjects, I used different strategies for interviewing them. Interviews of house staff interns, residents, and nurses, the group to which I had greatest access, utilized a two-fold strategy consisting of multiple informal/conversational interviews, and one or more formal/guided interviews. Interviews of private attending physicians, due to their busy schedules, were generally restricted to single one-hour formal encounters, and occasional serendipitous informal interviews in a hospital corridor. Interviews of hospital inpatients were also often necessarily short because of patients' poor health status and short hospital stays. Typically, these interviews lasted no more than 45 minutes and were often conducted in two sessions. Interviews with outpatients, which took place in either the clinic waiting room or an examination room, were all informal and conversational. Details of the interviews are summarized below in Table 3:2.

Table 3.2: Description of Interviews

	Formal Interviews			Informal Interviews		
	No. of Hours	Number of Inter-viewees	Range and Mean No. of Hours per Interview	No. of Hours	Number of Inter-viewees	Range and Mean No. of Hours per Interview
Interns/ Residents	32	18	1.0-3.0 Hrs. Mean=1.8 Hr	84	26	.25-3.0 Hrs. Mean=3.2 Hr
Attendings	18	13	1.0-2.0 Hrs. Mean=1.4 Hr	30	19	.25-2.0 Hrs. Mean=1.6 Hr
Nurses	51	32	1.0-2.5 Hrs. Mean=1.6 Hr	77	41	.25-2.5 Hrs. Mean=1.9 Hr
Patients	15	15	.75-1.25 Hr Mean=1.0 Hr	19	36	.25-5.0 Hr Mean=.5 Hr
Totals	116	78	-	210	122	-

Conversational interviews. Informal/conversational interviews were conducted throughout the entire data collection period as a means of solidifying relationships with staff members, validating data, and opening new lines of inquiry. These interviews proceeded in two overlapping stages. During the first three to four months of field research I conducted informal and conversational interviews with the medical directors of the clinic and rehabilitation unit, most members of the house staff, and most members of the nursing staff in each of the three research settings. The primary goal of these interviews was to build rapport and seek opportunities for future structured interviews and private observations. These interviews were unstructured and nondirective. I did, however, encourage providers to talk about topics that they, themselves, raised that focused on or related to difficult or good patients. I also conducted conversational interviews with patients in the outpatient waiting room and the rehabilitation unit in order to gain a general impression of the patient population at both sites. I neither tape recorded nor took notes during conversational interviews. Tape-recorded notes were made after each interview.

Drawing on information from prior observations and interviews, subsequent conversational interviews functioned to member check previous data and generate increasingly specific lines of inquiry. I asked providers to discuss specific topics of difficulty and to elaborate on their experiences with particular difficult patients.

Structured formal interviews. Structured interviews with house staff providers were conducted primarily during the period of focused observations (months 4-14), and began only after I felt comfortable that I had gained their trust. These interviews focused on examining staff members' cognitive and experiential understandings of difficult patients, and on identifying potential sources of difficulty in providers' lives and practices. Structured interviews with patients, which began shortly thereafter, examined principally aspects of patients' interactions with their doctors and nurses. All interviews with providers took place in a private setting; interviews with patients took place at bedside in the hospital. All structured interviews were tape recorded and later transcribed verbatim.

I tried to keep all formal interviews as conversational as possible. Interview schedules served as guides rather than as rigid directions for structuring the interviews. I always encouraged interviewees to elaborate on their answers and allowed them to digress at will.

Provider interviews. Provider interviews consisted of two parts. Part one consisted of a hand-out given to interviewees that summarized all the medical, circumstantial, and behavioral characteristics of difficult patients that providers reported to me in prior informal interviews (see Appendix I). Interviewees were asked to look at the list and identify the difficulties that they found most important or meaningful. The object of this exercise was to develop a typology of difficulty from providers' perspective. Their responses were probed with questions informed by Spradley (1979), Agar (1980) and Werner and Schoepfle (1987) for formulating questions about taxonomic elicitation and folk categories.

Part two of the interview consisted of a series of questions asking about providers' interactions with patients, their experience of difficult patients, their management of difficult patients, and their perceptions of aging (see Appendix II). These questions derived from what I considered to be potentially fruitful lines of inquiry developed previously in informal interviews with providers and in previous research (see Fineman 1991a). Interview times among house staff residents and interns were wide-ranging. Because I did not strictly direct interviews, providers were free to take as much time as they wanted. As a consequence, many of these interviews were conducted in two or three one-hour sessions.

Patient interviews. Formal patient interviews focused on patients' perception of their health status, their goals of treatment, their experience of their interactions with doctors and nurses, and their expectations of staff members. Due to the poor health status and brevity of hospital stays, these interviews were often necessarily brief, and usually lasted no more than one hour. The patient interview schedule is described in appendix 3.

The interview sample. The providers interviewed for this study were drawn from: (a) the total pool of 14 house staff interns, 12 residents, and 14 administrative medical faculty members of the internal medicine department of the hospital; (b) the total pool of 42 nurses (RNs and LVNs) on the day shift in the outpatient clinic, the acute care general medicine units of the hospital (7 East and 6 East), and the inpatient rehabilitation unit; and (c) from the estimated population of 160 faculty practice and private attending physicians who had faculty status or attended patients in the hospital.

I conducted formal interviews with 31 doctors including 10 interns (71% all interns), 8 residents (66% of all residents), 3 faculty administrators (21 percent of internal medicine faculty), and 10 faculty practice and private attending physicians (6%. of the total estimated population of private and faculty practice attending physicians at Mt. Sinai). In addition, formal interviews were conducted with 32 nurses, (11 LVNs and 21 RNs; 75 percent of all day-shift nurses in the three settings) including all 6 nurses in the general medicine outpatient clinic, five of seven nurses on the rehabilitation unit, 13 of 16 nurses on 7E, and 8 of 13 nurses on 6 East.

Formal interviews were also conducted with a small number of hospital inpatients who had been identified by providers as difficult. Although the goal of this project was to interview 30 patients, I was ultimately unable to do so because so many of them, due to their poor health status, their unwillingness to be interviewed, and the brevity of their hospitalization, either declined to be interviewed or could not be scheduled for an interview.

Description of sample. In terms of their age, sex, ethnicity, and race, the sample of staff members I interviewed represented a diverse group of people that was probably representative of the staff of Mt. Sinai as a whole. Thirty eight percent of interns and residents interviewed were female; sixty-two percent were male. House staff interns and residents represented 15 medical schools from around the country and internationally, but almost one-third came to Mt. Sinai from the state university system. About two-thirds of the sample were white and of European-American ancestry; about 20 percent were of Asian American ancestry; the remainder were foreign nationals. There were no African Americans in the

sample or among house staff in total. Ages of interviewees ranged from 27 to 44. The median age was 30.

Among the attending physicians interviewed, six were male; four were female; ages ranged from 35 to 65. The median age was 43. All were white and of European-American ancestry. Three were foreign born.

Among the nurses, about 40 percent were white and of European-American ancestry, about 27 percent were Latina, 20 percent were black, and the balance were Asian-American. Nurses' ages ranged from 29 to 57; the median age was 41.

Recruitment of sample. Interviewees for formal interviews were recruited in a number of different ways. House staff interns, residents, and administrators and nursing staff were initially recruited during the first three months of field work during the period of public observations and informal interviews. Subsequently, I continued to recruit house staff members after meeting them informally in case conferences, staff meetings, and rounds. Private and faculty practice attending physicians were among the last providers to be recruited for formal interviews. The attending physicians interviewed were recruited either because they attended patients who had been previously identified as difficult by a house staff physician or nurse, or because they were recommended to me by another physician as someone who might be interesting to talk to.

Based on conversations and formal interviews with doctors and nurses and based on conversations heard during rounds, case conferences, and staff meetings, providers identified many "difficult" and "good" patients. Over the course of field work, 78 patients were identified to me as being difficult. I interviewed 15 of them based on either of two selection criteria: (1) their status as extreme cases (chosen by five or more providers as being difficult or good; and (2) their status as typical cases who, by providers' definitions, demonstrated normative behaviors for difficult and good patients and illustrated the ways in which such patients are normatively managed.

Case Studies

Data from observations and interviews about difficult patients were supplemented by the medical records of provider-identified difficult patients. Twenty-eight case studies were compiled to illustrate and illuminate findings of this study. These cases were drawn from the sample of 78 patients identified by providers as being difficult. These case studies integrated historical information from patients' medical records with interview and observational data in an effort to examine the variety and complexity of difficult patients. They are reported on selectively here to illustrate mundane and extreme cases of patient difficulty.

Data Management

This study generated a large amount of qualitative data from observations and interviews. Tape-recorded notes made after observations and conversational interviews, and taped-recorded interviews were transcribed verbatim into a word processing format

that could be manipulated using the text analysis program, HyperQual (Padilla 1991). Lamentably, this software was difficult to use, ponderously slow, and insufficient to build theoretical constructs. As a result, all data were converted into *Word 5.1* files (Microsoft 1992), and with the help of the "search" feature of *Word*, all coding and analyses were performed manually. First, hard copies of all transcribed notes and interviews were manually coded. Then, multiple copies of these texts were made. Finally, chunks of coded data were filed in separate manila folders for visual inspection, further coding, and analysis.

Field Notes

Field notes were recorded systematically and followed a checklist suggested by Spradley (1980) and Hammersley and Atkinson (1983) for making comprehensive contextualized field records. Notes were organized temporally and tape recorded in a simple, straightforward, concrete, and usually timely manner. My dictation technique was to describe a sequence of events or conversation according to the sequence of events. I then added my own interpretive and analytical notes, which were separate from the description. These were transcribed into the word processor in upper case text to separate them from the observations.

I took notes openly when and where it seemed natural to do so, on occasions and in places where others were also taking notes, for example during rounds, case conferences, staff meetings, and in chart rooms. At other times I ducked into unused rooms, bathrooms,

or the hospital roof to dictate notes, which were later transcribed. Although it was my original intention to transcribe tape-recorded notes within 24 to 48 hours of observations or interviews, this did not happen. Indeed some interviews were transcribed weeks, even months, after the interviews were conducted. Transcription became a real problem and I eventually hired the services of a professional transcription service to help with this task. All transcriptions were checked by me for accuracy and faithfulness to the taped recordings. Most of the recordings were of high quality and so I was satisfied that the transcriptions were accurate and complete.

Data Coding

Data coding began shortly after data collection began. The rationale underlying the creation of codes was what might be called "modified induction;" that is, although some coding categories were developed prior to field work (based on previous relevant and allied research on noncompliance), most of the coding was guided by the inductive, empirically grounded approach advocated by Glaser (1978), which is inherently open-minded and context-sensitive. Following Glaser and Strauss (1967), I used principally two techniques of inductive analysis: isolating themes and categorizing through constant comparisons. Data were systematically coded into as many themes and meaning categories as possible. Then, as the number of categories reached saturation, I wrote rules that defined the parameters of the category.

I envisioned data coding as an iterative process that would drive ongoing data collection, “a form of continuing analysis,” as Miles and Huberman (1994:63) have written, in which initial codes were treated essentially as summarizing devices and secondary codes (which represented emergent themes) were constructs that helped to reduce data, build a cognitive picture, and lay the groundwork for further analysis by generating and fine-tuning questions that were used in later interviews. A coding list of about 60 clearly defined categories was initially developed to organize and cluster chunks of data. Throughout the coding process, some codes were dropped as unproductive; others were elaborated upon by subdividing them into subcodes, and new codes were developed as new lines of inquiry emerged.

Texts were coded by me and a trained medical-interview coder. At the beginning of the coding process all data sets were double-coded in order to reconcile differences in coding strategies between the two of us, to expand on or amend operational definitions and applications of codes, and to check reliability. Coding continued on an individual basis after intercoder reliability consistently was 85 percent or higher.

Qualitative Data Analysis

During data collection, qualitative data were analyzed following Strauss' (1987) coding paradigm in an effort to work out a theoretical ordering of providers' understandings of the conditions, strategies, tactics, and consequences of difficult patients. Then, when the data set was complete and concurrent with the beginning of the write-up, a final data analysis was carried out. This analysis, which followed closely the suggestions of Miles and Huberman (1994), depended a great deal on the use of displays such as matrices, which laid out the relationships among variables. The combining of analysis and writing is a difficult but perhaps profitable task. As Miles and Huberman have said, "the act of writing text as one ruminates over the meaning of a display is itself a focusing and forcing device that guides further analysis.(1994:91). While this may be true, the strategy was emotionally painful and logistically difficult to carry out because it left discovery of the ultimate conclusions of the research to be discovered only at the very end of the writing process. This discovery process virtually mandated rewriting the conclusions of this research a number of times.

Data interpretation was guided by use of specific tactics suggested by Miles and Huberman (1994) for generating meanings. I always tried to keep these in mind when looking at data, especially when data were elusive, ambiguous, or confusing. Some of these tactics included: counting and noting patterns and themes (doing content analyses and summing the frequency of a phenomenon in order to see trends, generate new leads, and discover anomalies), noting relations between variables, reducing or expanding categories of data by clustering or subsuming particulars into the general, by splitting variables, and by looking for intervening variables; making metaphors; examining the plausibility of putative explanations;

[illegible]

building a logical chain of evidence; and making conceptual coherence.

Quantitative Data Analysis

Quantitative analyses were used to compare differences and strength of association in the interview responses of doctors and nurses, LVNs and RNs, and interns/residents and attending physicians. Numeric data from coded interviews were entered into standardized forms for analysis using the statistical software package, *Crunch4* (Bostrum and Kahn 1991). Parametric and nonparametric statistical procedures for assessing group differences and for evaluating strength of association with groups were used as appropriate and are explained in detail in the text. In order to assess differences between doctors and nurses, for example, the chi-square and the Fisher's Exact Test were used.

My Biases

I recognized early on an inherent analytical bias in my work: a personal predisposition to look for and find patterns of order in data. Wax (1971) has called this bias the "holistic fallacy" (interpreting events as more patterned and congruent than they really are), a problem that results from what Miles and Huberman (1994:224) have referred to as "pattern-forcing exercises" such as clustering. Likewise, I found that I'm inclined to fall victim to, what Kahnemann and Tversky (1972) have called the "availability heuristic," the habit of being interested in and focusing on "vivid" data at the expense of investigating "pallid" data. As a consequence, I have in this analysis been alert to these problems and have on a number of occasions specifically eliminated from an analysis events or circumstances, evidence, or informants that were especially powerful to me but not necessarily representative.[7]

Negotiating Entry and Gaining Rapport

A number of researchers have commented on the importance and difficulty of gaining entry into elite professional settings and gaining trust and rapport with workers (see for example Bosk 1979; Mizrahi 1986). Ostrander (1993) has pointed out the difficulty of penetrating such settings because of the barriers that elites establish to separate them from the rest of society. I recognized early on in the planning of this project that negotiating entry and gaining rapport with providers and patients were critical issues and goals of this study. The present research plan was based around strategies to build rapport with staff physicians and nurses. The choice of sites, the research agenda, and the choice of research instruments all reflect my concern with gaining the participation and cooperation of the doctors and nurses.

In addition, I enlisted the aid and sponsorship of key people in the hospital including the Chief of Medicine and the medical directors of each of the clinical units in which I planned to work. My formal introductions to the new interns by the internal medicine director, to rehabilitation staff by the medical director, and to

nursing staff by the nursing director were crucial to establish my credibility and legitimacy in the hospital. Entry was also aided by my previous acquaintanceship with a number of Mt. Sinai staff members whom I met while enrolled in a clinical rotation with the hospital's geriatric assessment team.

Although I feared that being identified with hospital administration could potentially have adverse consequences for me (if, for example, staff members believed that my research was sponsored by hospital officials to spy on them), these fears proved to be groundless. While I did encounter occasional questions or comments about my sponsorship, it never prevented me from carrying on this study.

Gaining formal permission to do the research from department heads was only the beginning of the process of gaining rapport. Given the autonomy of the house staff, I negotiated individually with each of them to conduct observations and interviews. Requests for interviews were usually preceded by a request to merely follow along with a team on rounds. And ultimately, most team members felt comfortable enough with me after a few days to grant me permission to interview them.

Validity and Reliability

Concerns about validity are central to the design of any study. Although some interpretivist researchers have claimed that the notion of validity is useless because there are no facts to be verified (see Schwandt 1994 for a good discussion of this topic),

others take (for me) a more measured and moderate approach. As Miles and Huberman (1994:227) have said: " Qualitative studies take place in a real social world...[and] there is a reasonable view of 'what happened' in any particular situation."

This view advocates a research approach that focuses not so much on verifying reports as on increasing their trustworthiness and authenticity (see for example Guba and Lincoln 1981; Lincoln and Guba 1985). As Bernard (1988) has correctly and succinctly noted, validity can never be demonstrated, but it can be made more likely.

In this study, I followed some practical guidelines suggested by Miles and Huberman (1994) and Guba (1981) for increasing the trustworthiness of the findings. First, I have tried in this chapter to increase confirmability and objectivity by making my methods explicit; second, I have tried to increase the reliability and dependability of data by using consistent methods; and third, I have tried to increase the credibility of conclusions specifically by looking for negative evidence by soliciting comments from skeptics and identifying areas of uncertainly, by using a variety of data collection techniques (conversational interviews, structured interviews, observations) and data sources (physicians, nurses, patients, medical records) to triangulate data, and by observing and interviewing practically the entire population of interns, residents, and nurses at the research sites.

In addition, I also drew selectively upon a number of tactics outlined by Miles and Huberman (1994; see pages 230-243 for a complete explanation of these tactics) for testing and confirming findings and for increasing confidence that an analysis is authentic.

These included counting frequencies of occurrences in order to define the parameters of what was considered normative; making comparisons, like those between doctors and nurses; using extreme cases for verifying and confirming conclusions; checking out the merits of alternative explanations in interviews; and eliciting feedback form informants, a practice also endorsed by Blumer (1969) and Guba (1981).

Generalizability

It's hard to estimate to what extent the findings of this study are generalizable to other clinical settings. Although I believe that the sample of providers and patients was generally representative of providers and patients in other large urban hospitals, there were some obvious differences. First, the group of house staff interns and residents probably under-represents women and blacks and over-represents men and Asian-Americans. Thus it is impossible to calculate the extent to which the attitudes and beliefs of the providers I studied accurately represent those of physicians in the U.S. in general. Second, the group of patients I interviewed and observed definitely over-represents Russian émigrés. The degree to which, and the ways in which they are different from other. immigrant groups is impossible to assess.

In sum, it is difficult to assess the generalizability to populations of this study's findings and I view Mt. Sinai as a discrete and singular clinical setting. However, I believe that the findings of

this study will have a high degree of generalizability to concepts (See Lincoln and Guba 1985).

Endnotes

1 Following Miles and Huberman 1994:17, I believe that all methods that "work to produce clear, verifiable, replicable meanings from a set of qualitative data" are appropriate regardless of their antecedents.

2 These considerations included focusing the inquiry, fitting the paradigm to the focus, fitting the inquiry paradigm to the substantive theory used, specifying where and from whom data derived, specifying phases of inquiry, instrumentation, data collection and recording modes, and analysis procedures, planning the logistics and trustworthiness.

3 Work rounds showcased the nature of biomedical knowledge about patients and demonstrated how medical knowledge was hierarchically transacted among residents, interns, and medical students from successively more senior doctors to less experienced doctors. Dr. S.B., for example, was very explicit the way he wanted the interns and medical students to report on patients. During rounds he reminded all the members of his team that he wanted information to be given in a very specific manner and order. First, he said, he wanted a two-sentence summary of the case, presenting symptoms, and diagnosis. (These introductory remarks always took the same form, for example: This is a 32-year-old white woman with a diagnosis of X. Two days ago, after falling down a flight of stairs, she appeared in the ER complaining of symptoms A, B, C.)
Then he wanted a list of the diagnostic work that led to the differential diagnosis. These included mostly test results, for example, a description of blood gases, results of a CAT scan, or results of biopsy. This was to be followed by a short description of the patient's present condition, from the head down. Finally, he wanted a short report of the patient's progress on the night before the rounds took place.

4 ADLs refer to self-care "activities of daily living," that are used to evaluate functional independence. They include such skills as feeding, dressing, bathing, toileting, grooming, transferring (from wheelchair to bed), continence, locomotion, and communication. IADLs, instrumental activities of daily living, refer to basic tasks needed to support independent living. They include writing, reading, cooking, cleaning, shopping, doing laundry, climbing stairs, telephoning, managing medication, managing money and being able to travel.

5 This observation may or may not be true. My experience suggests that doctors' perceptions of patients are affected by more than their initial training, as will be shown later in this dissertation.

6 Observations open to investigation a considerable number of areas inaccessible through other methods. For example, it permitted me to see what people actually do as opposed to what they say they do and allowed me to understand people's actions in the context of their physical and organizational setting.

7 For example, I used evidence provided by the director of the Rehabilitation Unit, Dr. K.F., sparingly and with great caution because his descriptions of difficult patients were vitriolic and extreme.

8 I specifically timed the beginning of this field work to coincide with the starting date o of a group of new intem. I believed that starting at this time could also yield the benefit of gaining faster rapport because of the fact that they were new as well as I. It was not possible to follow this line of inquiry because the sample was to small to yield useful comparisons.

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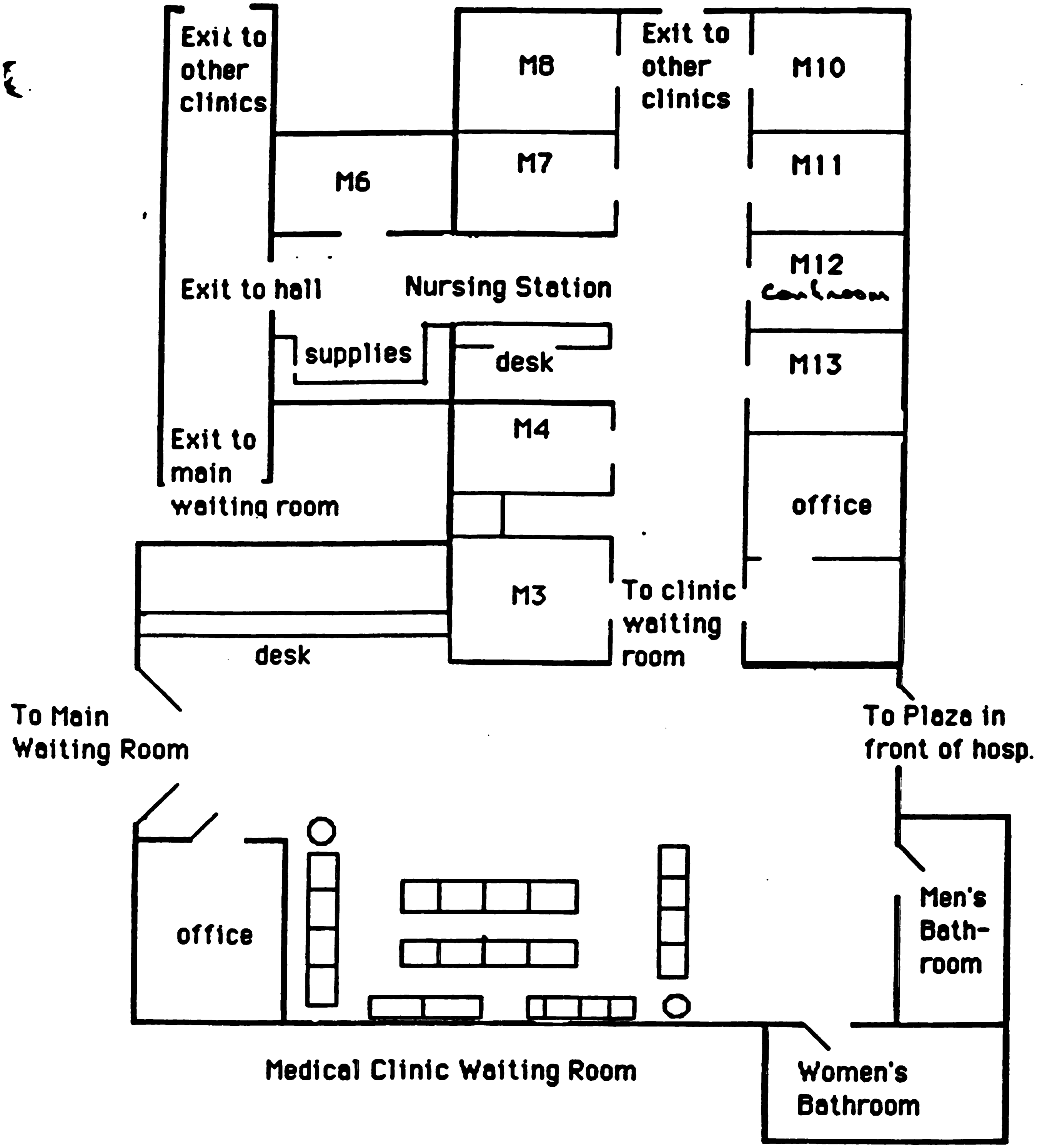
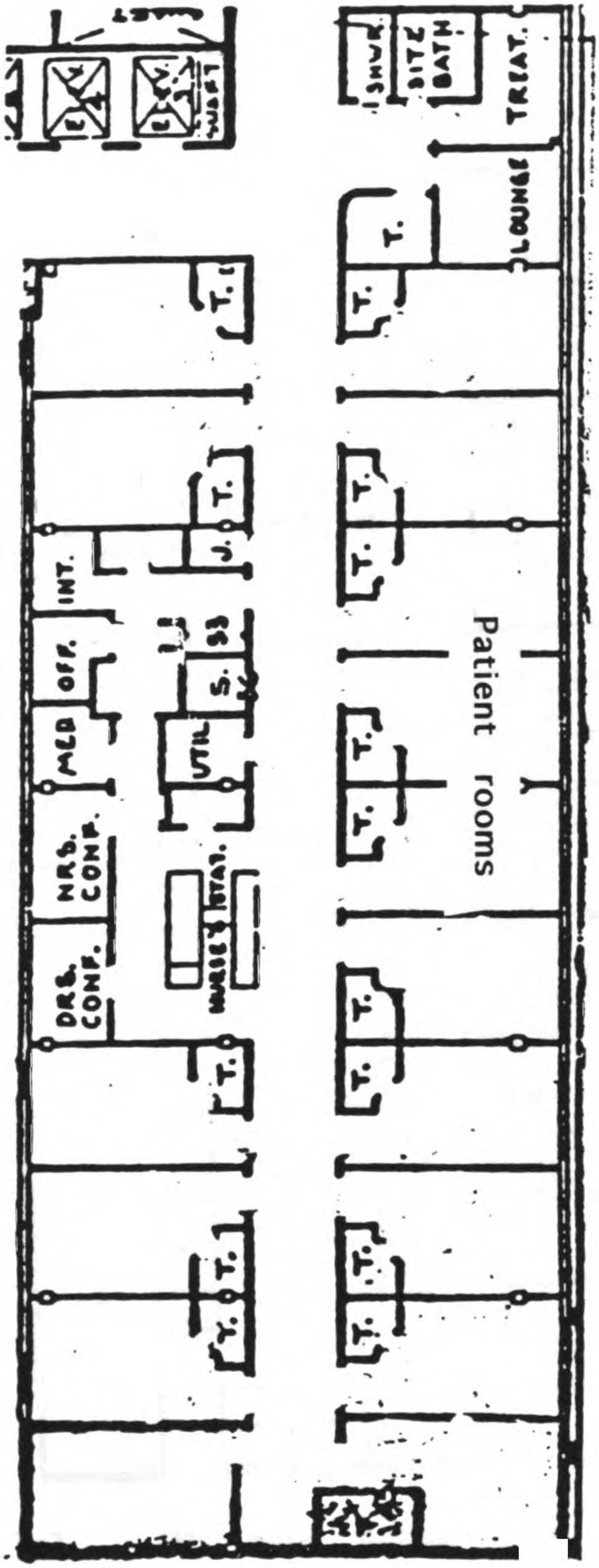


Figure 3:1: Mt. Sinai Outpatient Medical Clinic

Figure 3:2 Mt. Sinai Inpatient Unit



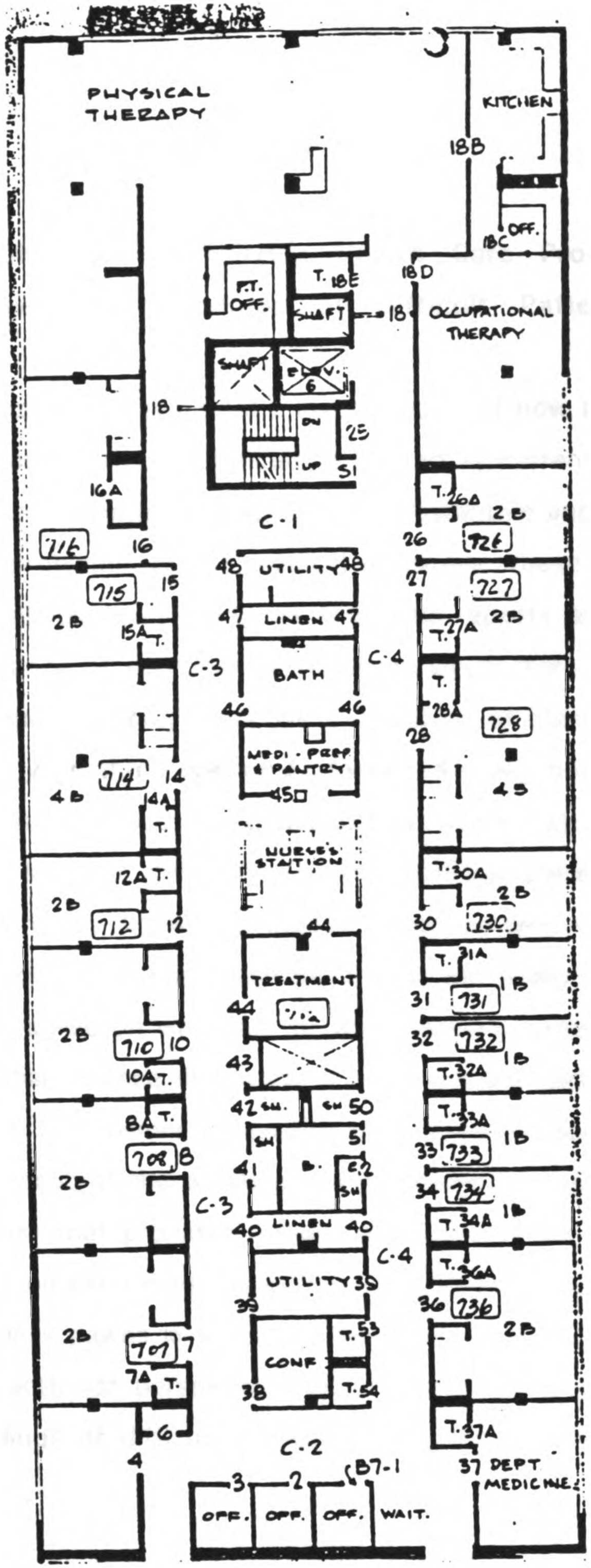


Figure 3:3 **Mt. Sinai Rehabiliation Unit**

SECTION II

DEFINING DIFFICULT PATIENTS: Health Care Providers' Subjective Understandings of Difficult Patients

Comprehensive and systematic investigation of how and why providers find some patients difficult is limited in current medical and social science research by a number of substantive and epistemological problems. In the medical literature, these problems include reliance almost exclusively on anecdotal reports and uncritical acceptance of nonreflexive reporting by doctors and nurses. These reports largely comprise a literature of blame and depend confidently on three previously described shaky but taken-for-granted assumptions about patients and providers: (a) that patients are the locus of difficulty; (b) that difficult patients comprise an eminently knowable--indeed a self-evident--diagnostic category of bad character traits and behaviors; and finally (c) that providers reliably agree on who and for what reasons patients are difficult. The social science literature is often equally didactic, but reaches different conclusions. Typically this research identifies providers as the locus of the problem and concludes (in the most extreme examples) that providers (especially doctors) are a power-hungry elite bent on exercising hegemony over patients, and that patients are hapless pawns in a medical exercise of power. By utilizing an interactionist perspective and by focusing on providers' emic understandings of difficult patients, the following three

[illegible]

chapters aim to redress some of the imbalances of previous reporting.

Chapters 4, 5, and 6 each examine a domain of providers' perceptions of difficult patients. Using interview data from long-term intensive interviews (informed by techniques of ethnoscience), observational data, aggregate nominal data, and case studies they describe and illustrate providers' shared and everyday understandings of difficult patients. Everyday understandings of difficult patients refer to the commonsense concepts that doctors and nurses develop and use in their everyday practices to understand difficulty. Chapter 4 examines the domain of medical difficulty; chapter 5 examines the domain of circumstantial difficulty; and chapter 6 examines the domain of behavioral difficulty.

The practical aim of these chapters is to build a systematic and comprehensive typology of providers' understandings of patient difficulty from providers' perspective. In doing so, the chapters establish a foundation for investigating the bases underlying providers' understandings of difficulty, and the personal, experiential meanings to doctors and nurses of difficult patients. The central observation of these chapters is that providers' understandings of difficult patients are multiple, complex, and often (but not always) shared.

The balance of this introduction explains in detail the methods used to elicit providers' subjective descriptions of difficult patients, the rationale for conceptualizing providers' descriptions within three broad domains of difficulty, and a quantitative overview of the three domains.

Data Gathering Procedures, Coding, and Analysis

In informal, unstructured interviews during the first three months of field research, I asked doctors, nurses, and other clinical staff members at each research site to tell me what difficult patients "mean to them" and how they "know someone is difficult." A composite list of 45 medical, circumstantial, and behavioral kinds of difficult patients emerged from this inquiry. Prior to beginning structured interviewing, this list was enumerated on a hand-out (see appendix I), which was then given to all interviewees at the beginning of each formal, structured interview. Interviewees were asked to examine the list and talk about any of the kinds of difficulty that were or were not "particularly important or meaningful" to them in their everyday clinical practice. In addition, I asked interviewees to report any other important and meaningful kinds of difficulty that did not appear on the list. In sum, procedures focused on eliciting each respondent's most important sources of difficulty. I encouraged interviewees to reflect on and talk about their own personal experience rather than speaking as representatives of the hospital or their profession. All were asked to illustrate their observations with personal stories about encounters with difficult patients. As a result of this inquiry, fourteen additional patient kinds of difficulty were added to the list; but with one exception, all of these proved to be idiosyncratic and unimportant. Thus 46 kinds of difficulty were ultimately identified in all: These included 13 kinds of medical difficulty; 6

TABLE II:1 Taxonomy of Providers' Descriptions and Assessments of Difficult Patients

Medically Difficult Patients

Depressed
Demented
Having Chronic Disease
Having an Uncertain Diagnosis
Having Ambiguous Code Status
Having Uncertain Disease Course
Having Multiple Diseases
Having Chronic Pain
Having Incurable Disease
Not Agreeing with Providers' Diagnosis or Assessment of Severity of Disease
Being Drug Addicted
Being Physically Disabled
Being Incontinent

Circumstantially Difficult Patients

Having a Difficult Family
Being Russian
Lacking Caregiving Support
Needing Language Translation
Needing Special or Difficult to Provide Medical or Social Services
Having Legal or Institutional Entitlement to Medical Care

Behaviorally Difficult Patients

Being Manipulative
Seeking Drugs
Working the System
Complaining of Pain
Seeking Secondary Gain
Sabotaging Plans
Doctor Shopping
Seeking Services Inappropriately
Being Uncooperative
Being Noncompliant
Refusing Treatment
Not Listening
Not Agreeing
Lacking Motivation or Commitment to Get Well
Demanding Inordinate Amount of Time or Services
Co-opting Provider's Role
Asking Too Many Questions
Seeking Too Much Attention
Complaining Too Much
Complaining About Trivial Problems
Being Overly Helpless or Needy
Being Physically or Verbally Abusive
Being Combative, Angry, Hostile, or Belligerent
Being Unreasonable
Somaticizing Illness
Being Irresponsible
Being an Ingrate
Lacking Respect

kinds of circumstantial difficulty; and 27 kinds of behavioral difficulty (see Table II:1).

Interviewees' responses were coded into one of three categories. A "yes" code indicated that an interviewee agreed that a particular patient characteristic was especially important; a "no" code indicated that an interviewee did not agree that a characteristic was especially important; and a "yes/no" code indicated that an interviewee made conflicting statements during an interview or made a statement in an initial interview that was at odds with one made in a subsequent interview. Altogether I recorded 32 yes/no responses, a small fraction (3.7%) of the 855 responses recorded in total. Because I interpreted these responses as conditional yes (yes, but) responses, I ultimately coded all of them as yes responses.

The coding procedure was based on a very literal interpretation of interviewees' statements. In order for a statement to be coded as a yes, interviewees had to explicitly point out a patient characteristic from the list and then indicate whether or not it represented a particularly difficult trait for them. In an effort to lay out fully the extent and breadth of attitudes and feelings about each difficult patient characteristic, data analysis focused on identifying descriptions of normative, extreme, and negative cases.

Three Conceptual/Analytical Domains of Difficulty

During an early stage of data analysis in the initial period of unstructured interviewing, I identified three discrete domains of [illegible] Book

difficult patient characteristics: (a) difficult medical problems; (b) difficult circumstances relating to patients' life and care; and (c) difficult patient behaviors.

The three domains of patient difficulty to be discussed presently--medical, circumstantial, and behavioral difficulties--did not emerge directly or explicitly from interviews with providers. These categories are my own. Indeed, when first asked about difficult patients, many providers unconsciously presumed that I was really asking about difficult behaviors only. Upon looking at the handout, for example, an attending physician said: "I thought you were talking more behavioral. To me a medically difficult patient is not problematic. [BZ, male, attending]

Another attending physician similarly minimized the importance of circumstantial and medical difficulties in comparison to behavioral difficulties. Patients' difficult behaviors, she reasoned, more so than medical and circumstantial difficulties, are difficult to manage.

> I would define difficult patients in your category of behavior rather than circumstantial problems, which can almost always be addressed in one way or another. The medical problems also can [be addressed] even if you don't know what's going on or don't know the course or whatever. I find those less difficult to deal with. It's really the behavioral situations....[CM, female, attending]

Despite such provider comments, I decided that these categories could be useful descriptive and analytical tools. In an attempt to systematically ascertain their validity, I asked 40 interviewees to comment on the relevance and utility of the three

conceptual domains. Upon consideration, most of them (37) approved of their use. One intern, (a key informant who often articulated the sentiments of many) affirmed the utility of the three categories and explained that some providers probably thought about patient difficulty in terms of difficult behaviors only because they had not reflected very much on the subject and as a result automatically talked about what was most obvious to them.

> I don't know if that many health care providers have good insight into the things that you have talked about [but] the fact is that there are different types of patient difficulty...Your observations [about this] are very correct. [GC, male, resident]

Perhaps the most persuasive evidence for the utility of the three domains is that interviewees, themselves, used them as descriptors. They referred to these categories often in their extended discussions of patient difficulty and used them to organize their thoughts. And, when elaborating on their understandings of difficult patients, fully two-thirds of providers drew upon patient characteristics from all three domains.

Quantitative Overview of Difficult Patients: The Relative Importance of Medical, Circumstantial, and Behavioral Domains of Difficulty

Difficult patients are a significant problem for providers and one that they report often. In this study the 63 providers interviewed cited 754 "yes" responses (agreed 754 times that

particular patient characteristics among the 46 listed were difficult for them; see Table II:2a). Doctors and nurses reported about the same total number of difficulties. Doctors cited difficult patient characteristics 420 times; nurses cited difficult patient characteristics 334 times. (The difference in the number of citations reported by the two groups is not statistically significant.)

Every provider cited at least some difficult patient characteristics. The number of difficult patient characteristics cited by providers ranged from 3-26. The mean number of difficult characteristics cited was 12.2 (s. d. = 5.5; [see table II:2b]).

As summarized in Tables II:2a, II:2b, and II:2c, providers defined patient difficulty largely in terms of difficult patient behaviors. Ninety five percent of interviewees cited some patient behaviors as difficult for them. The 27 behavioral characteristics they identified accounted for almost two-thirds of all citations of difficulty (see Table II:2a).

Difficult medical problems and patient circumstances were also significant, though less frequently cited, domains of patient difficulty. Ninety-five percent of interviewees cited some patient circumstances as difficult for them. The 6 characteristics of circumstantial difficulty identified by providers accounted for 19 percent of all citations of difficulty. Seventy-six percent of providers cited characteristics of medically difficult patients as being difficult for them. The 13 characteristics of medical difficulty also accounted for 19 percent of the total number of cited difficulties.

Table II:2a: Frequency of Reported Difficulties[1]

	Doctors N=31		Nurses N=32		Total Providers N=63	
	yes	no	yes	no	yes	no
Medical Difficulties	84	19	61	7	145 (19%)	26
Circumstantial Difficulties	61	7	81	14	142 (19%)	21
Behavioral Difficulties	275	37	192	46	467 (62%)	83
Total Difficulties	420 (56%)	63	334 (44%)	67	754 (100%)	130

Table II:2b: Number of Providers Citing Difficulty

	Doctors N=31	Nurses N=32	Total Providers N=63
Medical Difficulties	27	21	48
Circumstantial Difficulties	30	30	60
Behavioral Difficulties	30	30	60
Total Number of Providers Who Cite Difficulty	31	32	63

Table II:2c: Descriptive Quantitative Summary of Providers' Citations of Difficulty

	Doctors N=31		Nurses N=32		Total Providers N=63	
	number cited	mean (sd)	number cited	mean (sd)	number cited	mean (sd)
Medical Difficulties	0-5	2.7(2.1)	0-6	1.9(2.0)	0-5	2.3(2.1)
Circumstantial Difficulties	1-5	2.0(1.0)	0-6	2.5(1.5)	0-6	2.2(1.1)
Behavioral Difficulties	0-18	8.9(4.6)	0-17	6.0(3.9)	0-18	7.4(4.5)
Total Number of Citations per Provider	3-26	13.6(5.9)	4-24	10.8(5.2)	3-26	12.2(5.5)

Endnotes

1 "Yes" responses refer to the number of times that a difficult patient characteristic or cluster of characteristics was cited by providers as being especially meaningful or important. The number of yes responses cited by providers is often more than the total number of providers because providers cited as difficult more than one characteristic of a domain or subset of a domain.

CHAPTER 4

DEFINING DIFFICULTY:

Providers' Subjective Understandings of Medical Difficulty

Introduction

Research by practicing physicians represents medically difficult patients in one of two ways: First, a clinically based perspective, which sometimes refers to these patients as "heartsink" or "fat-envelope" patients, views medically difficult patients as patients who are "difficult to treat" for any of a very wide variety of reasons. These reasons include having a difficult medical history, having multiple vague symptoms, needing many tests, exams, or medical consults, malingering, having an "obsession with disease that cannot be proved or disproved," and having a "psychopathic/sociopathic/psychiatric" disorder. Second, a presumably more enlightened psychiatric perspective conceptualizes medical difficulty largely as an artifact of doctor-patient interaction. Patients become medically difficult, this perspective reasons, because patients may have unrealistic attitudes about and expectations of treatment or remission, or they become medically difficult because physicians may respond to unexplained symptoms and severe untreatable disease with feelings of helplessness, frustration, or inadequacy (Goldberg 1993; Lechky 1992; Mayou and Sharpe 1995). Neither of these positions seem to be particularly well thought out or conceptually coherent.

This chapter attempts to formulate a clearer framework for conceptualizing the domain of medical difficulty. Based on interviews with doctors and nurses, it suggests a typology of medical difficulty consisting of six subtypes. The chapter then describes providers' reasons for why medical difficulty is problematic, and describes their moral assessments of medically difficult patients. The chapter concludes with a case study of a typical medically difficult patient.

The Domain of Medical Difficulty

Medically difficult patients are patients whose medical status renders them difficult to providers. This section examines providers' shared understandings of medical difficulty and medically difficult patients. It focuses on identifying the characteristics of patients' medical status that providers perceived as being difficult, and the kinds of patients with whom they associated these characteristics. The analysis begins with a numerical summary of the relative importance of this domain of difficulty. It then uses interview data to elaborate on the meanings of providers' definitions of medical difficulty. Finally, a case study illustrates a typical case of a medically difficulty patient. Throughout, the analysis focuses on revealing the doctors' and nurses' overlapping and shared understandings of medical difficulty.

Medical problems represent an important source of difficulty for providers. Eighty-four percent of doctors and 66 percent of nurses identified at least one characteristic of medical difficulty

that was very meaningful to them; and most reported more than one. The mean number of medical difficulties reported per provider was 2.3 (s.d. = 2.1). The range of medical difficulties reported per provider was 0-9.

Providers identified 12 kinds of medical difficulty (see Table 4:1). These included, in order of the number of providers that reported them: depression (40%)[1] ; dementia (37%); chronic disease (27%); uncertain diagnosis (27%); ambiguous code status (22%); uncertain disease course (19%); multiple diseases (17%); chronic pain (14%); absence of cure (11%); lack of agreement between staff and patient about nature or severity of disease or about treatment plan (8%); drug addiction (5%); patient physical disability (3%). Incontinence was discussed by two providers as something that they thought others perhaps found difficult.

For purposes of analysis, I aggregate these 12 characteristics into six conceptual categories (see Table 4:3). These include, in order of their importance (as measured by the number of providers citing factors of them): (1) cognitive/psychiatric problems, (2) problems of chronicity, (3) problems of uncertainty, (4) multiple medical problems, (5) absence of cure, and (6) other problems. I discuss only the first five of these categories, which represent 93 percent of all provider reports of medical difficulty.

Table 4:1 Conceptual Categories of Medical Difficulty

	Doctors N=31 providers citing yes responses	Nurses N=32 providers citing yes responses	Total Providers N=63 providers citing yes responses
Cognitive/ Psychiatric Problems:			
depression	16	11	23
dementia	16	9	25
Problems of Chronicity:			
chronic disease	11	6	17
chronic pain	3	6	9
Problems of Uncertainty/ Unpredictability			
uncertain - diagnosis	8	9	17
uncertain code status	10	4	14
unpredictable course	8	4	12
Multiple medical problems	5	6	11
Absence of cure	5	2	7
Other Problems			
lack of consensus	1	-	1
drug addiction	1	2	3
physical disability	-	2	2
Totals	84	61	145

Cognitive/Psychiatric Problems

Cognitive/psychiatric problems refer specifically to depression and dementia (schizophrenia was occasionally also

mentioned, but very few schizophrenic patients were seen at this hospital). Cognitive problems were the most important category of medical difficulties. Thirty-six providers (21 doctors and 15 nurses; 57% of providers) cited cognitive problems as being very important to them a total of 48 times (representing 33% of all citations of medical difficulty).

For the most part, providers at this institution linked cognitive problems to elderly patients in general, and to elderly Russian patients in particular.[2] To a lesser degree, dementia was also associated with AIDS patients, chronic alcohol abusers (with Korsakoff's syndrome for example), or patients with other types of organic brain disease. The following representative comment by a charge nurse makes clear providers' associations among depression, old age, and Russian immigrant status. It also illustrates their shared belief that the root of depression among elderly Russians was culture shock--brought about by factors such as forced immigration to the U.S.,[3] loss of independence, dependence on uncaring children, unrealistic expectations of life in America, lack of familiarity with American life-ways and customs, and inability to speak English.

> Most of them [elderly Russians] are very depressed because they come here and they have this culture shock, you know coming to a new country. And they think that America will give them all the things that they want, and it's not true. A lot of them...have not had good medical care, you know, and maybe their children are very busy trying to find work and if they do find work they are very busy with their children, and work, and school. So they're left alone again, you know. [EL, female, RN, nursing administrator]

Problems of Chronicity

Chronic disease. Chronic medical problems refer to problems associated with treating the medical dimensions of chronic disease and chronic pain. Chronic disease refers to all the diseases commonly acknowledged as being chronic, from arthritis, to renal disease, to hypertension, to cardiovascular disease, etc. Medical difficulties associated with chronic pain refer specifically to the difficulty of understanding the arcane medical aspects of pain assessment and management. These problems represented the second most important category of medical difficulty and were cited by 27 providers (14 doctors, 13 nurses; representing 43% of providers) a total of 26 times (representing 18% of all citations of medical difficulty).

When doctors and nurses talked about the difficulty of chronic disease and pain, they were really talking about the difficulty of managing the treatment and care of _people_ with chronic disease and pain. And again, as with cognitive problems, who they were generally talking about were people who were elderly,[4] elderly and Russian, or people with AIDS. (This hospital had a first-rate AIDS unit that provided state-of-the-art aggressive acute symptomatic care for HIV and AIDS patients. These patients were generally part of the teaching services and were therefore visited daily by staff residents, interns, and nurse administrators. It is not surprising then that many providers at this institution considered AIDS a chronic disease.)

A resident summed up the association between chronic disease and old age:

> Well, to be somewhat facetious, they [elderly people] get sick more. They have chronic illness. [DC, male, resident]

Chronic pain. Chronic pain represents a special type of chronic medical difficulty for providers because it raises moral as well as medical issues for them. Medical difficulties associated with chronic pain refer specifically to the difficulty for providers of understanding the arcane medical aspects of pain assessment and managemnet. Moral difficulties, in contrast, have more to do with providers' unease and uncertainty about the necessity and appropriateness of prescribing narcotic pain killers for many patients. The difficulty arises in large part from the unavailability of medically "objective findings" to locate and measure pain in order to corroborate patients' "subjective reports" of it. As a consequence, patients with chronic pain were difficult as well because providers often regarded them skeptically and suspiciously as potential drug abusers. Although the moral dimensions of chronic pain are discussed elsewhere in the dissertation,[5] I raise the issue here as well because providers regarded pain patients suspiciously even when they acknowledged that such patients had painful diseases (like cancer or sickle cell anemia) that often required large or continuing doses of pain medication. "The question is," an intern asked about a sickle-cell patient who requested IV Demerol in place of the skin patch that was prescribed, "Is this real pain or [is she] seeking drugs?" In a powerful demonstration of his skepticism and

suspicion, he later remarked to me: "She wasn't like Mr. B. down the hall who doubled over and was moaning 'Oh God, Oh God.' She was just staring at the TV. But when I asked how her pain was, she said it was nine over ten."

Providers associated chronic pain with depressed (hence elderly) patients, patients with sickle cell anemia, and especially with Russian patients. It was a running joke among providers of this hospital that the first (indeed the only) Russian word they really needed to learn was *"belit,"* the Russian word for pain. The clinic charge nurse explained:

> As soon as you ask [the Russians] 'belit?', they start in and say 'belit' and show you everywhere they can find on their bodies. So, its very hard to focus. The chest pain will go to the neck pain and then it will go to the head pain, and then all of a sudden you're taking about total body pain. Everything is belit. So I'm even afraid to bring up the word "belit" because everything is going to be belit. It's like a joke now. [EL, female, charge nurse]

The humor of this situation was lost on no one. For the annual hospital house-staff Christmas party, the interns put together a thoroughly tasteless but very funny video on how to recognize and treat a new disease they claimed to have discovered--TBB, total body belit. "I think," an intern claimed, "a lot of the Russians, they want to have pain...." [WB, male, intern] And another intern concurred:

> [T]hese Russian patients, I'll listen to their complaints of chest pain and it will sound a lot more gastric [than cardiac] and I'll say [to them] 'This doesn't sound like there is something wrong with your heart. It sounds like something gastric. We'll give you Maalox.' I figure the average American

> patient would probably say, 'Oh, that's great. There's nothing wrong with my heart?' The average Russian patient seems a little disappointed, you know. [MS, male, intern]

Among a small minority of providers (3 doctors and 1 nurse), chronic pain was associated with patients (referred to by one intern as "the pain people") who were perceived to be depressed, suffering from an unspecified personality disorder, or having an altered world view, all of which were presumed to have resulted from the exigencies of dealing with chronic pain. Two interns explained:

> [With] people who are in chronic pain...there's often sort of this learned helplessness about it and depression that goes along with it...I think that also impairs sometimes people's ability to be rational, to make decisions about their health care...And I think that at times a person's judgment is impaired.... [RS, male, intern]

> Patients with chronic renal failure, I would say, universally develop personality disorders over a period of time because of their disease...I really don't know what all goes on but I think real pain that's ongoing is certainly a cause for people to have a different perception of their world...A lot of times they expect instant relief and if it's not forthcoming they return again and again and again complaining of the same problems. It's a real problem. [CN, male, intern, oncology]

Problems of Uncertainty/Unpredictability

Predictability and certainty are highly valued in medicine, which its practitioners consider a science. Uncertainty, as Parsons (1951) and Fox (1957) have shown, is disparaged and feared by doctors because it vitiates definitive diagnosis and prognosis in a

culture that demands optimism and solutions, and because it poses serious problems of communicating the unknown to patients. Fox, has additionally documented how medical schools socialize students to cope successfully with uncertainty.

Certainty and predictability were especially prized by the teaching staff of this hospital because these qualities often served as markers of medical "textbook cases," which attendings and residents valued and sought out to illustrate for students and interns general principles of pathology, diagnosis, and treatment. As a consequence, teaching staff considered textbook cases to be fortuitous and oftentimes referred to them as "ideal."[6]

Providers also defined as problems of uncertainty any case in which diagnosis, medical status, or course of disease, treatment, or prognosis were unknowable or unavailable. Together these three factors represented the third most often-cited category of medical difficulty, cited by 26 providers (15 doctors and 11 nurses; representing 41% of providers) a total of 43 times (representing 30% of all citations of medical difficulty).

Uncertain diagnosis. Diagnostic uncertainty arose in cases in which lab values were ambiguous or contradictory, medical records were unavailable and patients' medical history was unknown, and where symptoms were unclear or contradictory. Uncertainty of diagnosis was the most important characteristic of medical uncertainty. Seventeen providers (8 doctors and 9 nurses; representing 27% of providers) agreed that uncertainty of diagnosis was very difficult. This is not surprising given the central importance of unambiguous diagnosis in clinical practice. Indeed, physician perceived certainty of diagnosis as the central issue, aim, and responsibility of clinical practice, referred to by one physician as "the big goal" of practice. [CH, female, intern] without which appropriate treatment is conjectural and certain course is impossible.

Uncertain/unpredictable disease course. Uncertain medical status or unpredictable course of disease was also considered to be a difficult medical problem and was reported to be so by 12 providers (8 doctors and 4 nurses; representing 19% of providers). Providers defined uncertain course of disease as cases in which accidental or unexpected complications occurred, cases in which standard approved treatments didn't work, or cases where patients had "waxing and waning cognitive capabilities." Providers anticipated medical uncertainty (thereby making it less uncertain) among elderly patients. In the following interview excerpt, a resident sadly described what he considered to be a difficult case involving an AIDS patient with a difficult to predict course of disease:

> [This patient was] unusual because [he] was not responding along the usual course. He was started on the new PCP drug. He did get better [and] he was treated as an outpatient. He improved and felt better for about two weeks. And then what happens with this drug sometimes, which we are now learning, is that they almost get better and the bug becomes resistant and then it gets worse. And I think that that's what happened to him. But it's certainly the standard of care. It's what they do at ward 86 [at SFGH]. The most expert AIDS doctors there are still using this drug and it's very effective. It's just that he

> was a rare case where he got resistance and it got worse on him. And that is frustrating for the doctors as well. [JJ, male, resident]

Uncertain code status. The last factor of medical uncertainty is uncertain code status. Code status refers to patients' official and designated status (recorded in the medical chart) regarding their wishes (or, in cases where patients have lost decision-making capability, the wishes of their family or designated surrogate) to be resuscitated and/or intubated following a cardiac arrest. Uncertain code status was reported as difficult by fourteen providers (10 doctors and 4 nurses; representing 22% of all providers) . In general, problems of code status centered around coordinating and reconciling disagreements about the appropriate code status of patients. Disagreements centered around the question to code patients as full code or no code. Full code patients were understood to have order to resuscitate; No code patients were understood to have orders not to have intubation (DNI orders) or resuscitation (DNR orders). Disagreements occurred between staff members and families, between attendings and house staff, and between physicians and patients. Among house-staff physicians such disagreements were understood specifically as conflicts with attendings, whom they perceived did not appreciate their expertise.

> I've had attendings jump down my throat for getting involved in [code] issues that they think I have no right being involved in with their patients. Often times it doesn't matter how much of that you do, the attending's unwilling to even consider that in the issue. [SB, male, resident]

Among nurses, the problem of ambiguous code status involved lack of agreement among physicians, nurses, families, and patients.

> [A]t times I find [ambiguous code status] difficult because you've got patients who had said--or you can just see that they really are tired--that they want to go peacefully. And...the family or the physician can't let them go. It becomes a problem. [MM, female, RN]
>
> Code status is also [an issue that involves nurses] with the family and the patient. Some of the time, when [patients] come in without a directive, the family would like to have a no code [a medical order to not resuscitate (DNR) or intubate (DNI) the patient] but the physician is not at that point into it. We have had several patients that have come in with a [DNR, DNI] directive and we still have to call the doctor. So, you know, I would have a little problem with that. [R, female, ass't head nurse]

Problems of uncertainty were perceived by providers to be especially acute among elderly patients, whose health status was often fragile and unpredictable, whose diagnoses were often confounded by medical cascade, and whose unambiguous code status was critical because they were especially susceptible to "code" (have a cardiac arrest) in the hospital. Problems of uncertain code status arose particularly for elderly patients because chronological age alone was sometimes used as an important medical rationale underlying recommendation of a no-code status. The example of Mrs. C illustrates:

An example of difficult code status, Mrs. C. Mrs. C. was an 87-year-old white woman with a prior history of arteriosclerotic heart disease and congestive heart failure. In 1989 she consulted a

physician for the first time in 17 years complaining of shortness of breath and edema in her ankles. She was diagnosed at that time with atrial fibrillation and masses in her breast and subsequently underwent a radical mastectomy of her left breast. She was currently taking Digoxin and Lasix for heart disease and Valium and Halcion. Her son reported that up until the present time, Mrs. C. had been in excellent health, living alone, and totally independent although she had recently complained of some difficulty walking.

On September 18, Mrs. C. suffered a right CVA (cardiovascular accident, or stroke) while at home. She wasn't found until two days later when her son, after not being able to reach her, called 911. When found by the fire department, Mrs. C. was verbally nonresponsive. She was diagnosed in the hospital as having "significant right hemiparesis with aphasia."

On admission the resident on duty discussed with Mrs. C.'s son the issues of CPR and intubation in light of her severe CVA and her poor prognosis for full brain recovery, her age, and the dangers of doing CPR (for example, broken ribs or sternum and loss of neurological function). Clearly, he believed that she should be coded DNR/DNI. Her son, however, stated at that time that she would nonetheless "want to be alive" and that all resuscitative measures should be taken. To the doctor's dismay, she was as a result listed as full code.

The following day, on September 21, her attending physician, Dr. D. discussed Mrs. C.'s code status with her son. He writes in his notes: "Code status discussed at length with son--No code decided--I agree. But on that same day a nurse notes in nursing notes: Patient

following commands. Not sure, but patient subjectively seems more aware of surroundings...scans visually and follows with eyes...helps me sit her up."

The following day, despite her noted improvement the night before, the resident in charge of the house team assigned to Mrs. C.'s care affirmed the rightness of the code decision. "She's 87 and she has shown no improvement in the last four days."

Then one day later, on September 23, Mrs. C.'s status had clearly improved. Dr. D. notes: "She responds to commands and apparently recognizes me." Yet, in spite of her improvement, Dr. D. still recommends no-code status. "Although patient is no code, care is definitely more that comfort care, fluids, antibiotics if indicated." An intern adds: "Code status: patient to receive pharmacologic antibiotics only, no pressors."

Multiple Medical Problems

Eleven providers (5 doctors and 6 nurses; representing 17% of providers) reported that patients with multiple medical problems were often difficult. They reported that multiple diseases or medical problems constituted difficulty because it complicated the management of medical and nursing care. Providers associated the occurrence of multiple medical problems with late life. When providers talked about medically difficult patients, they were often talking about elderly people. I also include in this category what one physician referred to as "medical cascade," the quick and usually irreversible onset of multiple medical problems and deterioration of health, especially in old age.

> Sometimes they've fallen down at home, in their feces and when they come in, they got bed sores, a demented illness, they just don't know what's going on, they're very confused. They have multiple diagnoses. They came in with altered mental status, with a history of CVA, cancer of the prostate. So I mean you're not only looking at one, you're looking at four different things. They're difficult, they have too many things going and that's what makes them really crazy. [R, female, ass't head nurse]
>
> And in the long term, physical problems are also hard to deal with especially the ones who develop multiple medical problems where....sometimes it's a trade-off as to whether you can help. You either will be able to do surgery on the knee but to do that you have to consider what kind of stress its going to place on the cardio-vascular system. It's a balancing act and sometimes they're not very good helping to give the outlook you'd like to know, what they'd like to do. [CH, male, chief resident]

Absence of Cure

Absence of cure was reported by a small number of providers as being difficult (five doctors and two nurses). In the main, absence of cure was not perceived as being a problem. Indeed, it prompted more negative cases than any other characteristic of medical difficulty. Seven doctors (23%), for example, reported that absence of cure was not a difficult problem for them. Perhaps this was so because many of them did not consider curing patients to be a primary objective of care. In fact, many providers said that expectations of cure were unrealistic, naive, or unschooled, and

often attributed such expectations to uninformed patients. Because providers perceived the difficulty of incurable patients essentially as a problem of patients with unreasonable expectations, rather than as a problem of patients dying, it really represents a behavioral difficulty rather than a medical one. I mention it here as well, however, because some patients who providers saw as having unrealistic expectations were nonetheless also very sick. AIDS patients, in particular, fell into this category.

Why Providers Perceived Medically Difficult Patients as Problems

This section examines the reasons why doctors' and nurses' perceived medically difficult patients as problems. These reasons comprised pervasive themes in most of their accounts of medical difficulty. In their attempts to explain why factors of medically difficult patients were indeed difficult, these reasons typically followed the word "because." Medical difficulty were perceived to be so because: (1) their medical status complicated or impeded management of their care; (2) their medical status prevented providers from establishing rapport with them; and (3) their medical status provoked in providers negative personal feelings of helplessness or failure.

This analysis has two primary aims: (1) to draw together succinctly the commonalties among doctors' and nurses' disparate accounts of the five dimensions of medical difficulty; and (2) to illustrate the common themes that underlay their explanations of medical difficulty.

The three themes discussed here are essential to understanding the reasons why providers perceived patients as being medically difficult. These themes appeared in 107 out of 135 (79%) of providers' explanations for why medically difficult patients were problematic. (The actual number of medical difficulties that these themes explain is probably somewhat higher than 79 percent because the denominator of 135 includes some reports for which there were no verbal accounts.)

Complicating/Impeding management of patient care. The most often cited of doctors' and nurses' reasons why patients were medically difficult was that the patients' medical status complicated or impeded management of some aspect of their care. This explanation represented 61 percent of all providers' explanations of why medically difficult patients were difficult. In particular, providers gave this explanation to explain the difficulty of problems of uncertainty, problems of chronicity, and cognitive/psychiatric problems.

Providers agreed that demented and depressed patients were difficult because their dementia and depression exacerbated the difficulty of managing their medical problems, making these patients very difficult indeed. Providers reported, for example that depressed patients inappropriately refused treatments and consent procedures. Demented patients were reported to be dangerous, noncompliant, difficult to schedule for labs and tests, difficult to prescribe for, difficult to supervise physically, and difficult to discharge to other institutions. The following remarks by a chief

resident and an RN illustrate some of the ways in which doctors and nurses thought depression and dementia complicated patient care.

> Cognitive impairment from mild forgetfulness to dementia are challenging because you have to think about how to...take someone with high blood pressure who you would like to treat, you have to think of a regimen that will work well for them that will not be too difficult for them. For example, they're not going to be able to take a medication three times a day. [CH, male, chief resident]

> Well, you have to treat them in a different way, you know. Like you can't tell a demented patient, 'You can't leave that place,' because one way or the other, she's going to leave and she's going to wander around. And you can't say, 'I'm going to call the security now,' you know. That's not going to get [you] anywhere. [EL, female, head nurse]

To take one more example, doctors and nurses also agreed that patients with chronic disease and pain were difficult because their medical status complicated or impeded aspects of their management. Patients with chronic disease, for example, were reported to sometimes undergo unspecified pathological personality changes that created behavioral problems. Patients with chronic pain were reported to be difficult to assess and treat. In the following three examples, two interns (one illustrates an extreme case) and an LVN talk about the difficulty of caring for patients with chronic disease and pain.

> One other kind of difficult patient is the patients with chronic disease...Patients with chronic renal failure over a period of time develop, I would say, universally develop personality disorders because of their disease. They [are] red flag[s] to me...A patient who [is] on dialysis would be a very difficult

> patient to deal with...I think part of the dialysis is a resentment. A lot of time they feel just absolutely terrible. They're placed on a dialysis schedule. They're dependent on the machines, they're dependent on the workers. But people want to help them. They have a tremendous ability to manipulate. They can withhold care from themselves by not coming to dialysis which causes all sorts of problems which will wind them back up and they wind up back in the hospital. I don't know, I think everybody who has a chronic problems develops altered perceptions of the world because of their problem. [CN, male, intern]

> As a physician, it can be difficult to work with them because you may not agree on what is really best for them. Even simple decisions. [I might say to a patient, for example] 'It's best that you get up and walk some everyday so that you can get your circulation going and you don't get bed sores or DVT's or pneumonia.' And they may not want to do that. You have a hard time convincing them that it's really a simple way for them to prevent a lot of serious complications and they may be unwilling to do it for irrational reasons. Chronic pain is usually associated with that. [RS , male, intern]

> You have people who want it [pain meds] every hour and they're not supposed to get it every hour, and you have a hard time convincing them [of] that. [They will say:] 'Well my doctor said I could have it when I have pain.' But they don't realize there's a time span for pain. And that part could be difficult. [AY, LVN, female]

Negative personal feelings of helplessness and failure.

Feelings of helplessness constituted the second most often cited explanation for why medical difficulties were problematic for providers (cited in 21 percent of providers' accounts of medical difficulty) and was particularly associated with problems of uncertainty and chronicity, two medical circumstances that

engendered feeling of impotence and insecurity. Two doctors illustrate:

> [T]he difficult patient that presents a problem that you can't figure out medically quote, unquote, makes you feel medically inadequate because often times you don't know if the patient presents the problem as difficult for anybody as difficult for you and you just can't figure it out. And those that are stressful patients. [SB, male, resident]

> I think the things like uncertain diagnosis are a problem in that as physicians or me even, feel a kind of failure of sorts. [CH, female, intern]

Inability to establish rapport. Doctors and nurses agreed that inability to establish rapport with patients was a principal explanation for why medically difficult patients were problematic, especially as an explanation for why depressed and demented patients represented problems. Many providers felt that depression represented an unbreachable barrier between themselves and their patients. They describe depressed patients as being "closed off" [JR, male, intern] or "withdrawn," [MM, female, RN] circumstances that exacerbated treatment difficulties because they made it difficult for them to "find out what's wrong" [SL, female, RN] with patients or prevent them from establishing rapport and a therapeutic alliance with patients, a situation that in typical circumstances left providers feeling that they could not communicate with patients, a circumstance that in some cases doctors felt exacerbated misunderstandings of unrealistic expectations and in an extreme case, left the doctor emotionally uninvolved. Three statements from

doctors and a nurse illustrate. The first two represent normative views; the last, made by an intern, expresses an extreme view:

> I think a lot of patients are depressed and we don't deal with depression because a lot of times with depression they allow us to not intervene because, you know, they're all withdrawn. [MM, female RN, head nurse]
>
> With demented patients you can't have any interaction with them because they're hardly there. [JR, male, intern]
>
> [T]here's a lot of people who are just sort of depressed and apathetic and they just don't care so much. And those are difficult patients to do because if someone's not interested in taking care of themselves, it's hard for me to get real excited about taking care of them, too, particularly when you have time demands on you. [RS, male, intern]

In sum, three reasons cropped up again and again in doctors' and nurses' accounts of medical difficulty to explain why patients were medically difficult. As will become clear, these explanations of difficulty will appear over and over again throughout the dissertation. They (together with a couple of others) constitute pervasive themes in most providers' accounts of all kinds of difficulty.

Providers' Moral Assessments: Deciding Who is Sick and Who is Bad

Doctors and nurses assessed their understandings of virtually all difficult patients along at least two dimensions: First, they assessed patients along an existential dimension, which helped them grapple with the problem, in cases where the patient's identity was

ambiguous or multiple, of determining a patient's preeminent identity as a difficult patient: determining, in other words, whether a patient was preeminently medically, circumstantially, behaviorally difficult. This was not always an easy matter because many if not most patients were difficult for more than one reason, and were perceived by providers to have more than one kind of difficulty: They might, for example, be medically and circumstantially difficult; or medically and behaviorally difficult; or circumstantially and behaviorally difficult. Uncooperative AIDS patients, for example, were perceived by providers as being both medically and behaviorally difficult. Providers' attempts to find a preeminent identity for such patients, and to resolve the dilemma created by their attendant uncertainty and ambiguity, involved a complex chain of decision making that rested on consideration of patients medical status, biography, behavior, and life circumstances, and on consideration of their professional standards of ethics, perceived responsibilities, and temperament. This process is fascinating, but exposition of it is beyond the scope of the present work.

Second, providers assessed difficult patients along a moral dimension. In an effort to know and explain why their patients were difficult, they subjectively assessed the intent underlying their patients' difficulties. Their moral assessments of patients' intentions, in other words, served as a means of making patients' perceived difficulties meaningful to them. Patients who doctors and nurses perceived to be unintentionally difficult, were concurrently perceived by almost every one of them to also be sick. Such patients

were rarely blamed or held accountable for their difficulties. In addition, these were patients for whom doctors and nurses accepted full professional responsibility.

In contrast, patients who doctors and nurses perceived to be intentionally difficult, were concurrently perceived by almost every one of them as miscreants. Indeed, their difficulties were viewed by most providers as acts of deliberate and calculated misbehavior, defiance, and deviance. Intentionally difficult patients, in essence, were seen as moral transgressors and labeled as being bad. Such patients were almost always blamed and held accountable for their difficulties, and very often providers absolved themselves of responsibility for these patients.

Doctors and nurses generally perceived that medically difficult patients were unintentionally difficult, and therefore legitimately sick, blameless, and deserving of care. Most agreed that the definitive unintentional medically difficult patient was the demented patient. Some medically difficult patients, however, presented problems because assessment of their intentions was uncertain. This was true particularly of pain patients and drug addicts.[7]

A Case of Medical Difficulty

The following brief case study illuminates providers' descriptions of medical difficulty by underscoring some of its central features, and by shedding light on some of the practical and theoretical issues it raises. Mr. J., was singled out as being difficult

by four providers: a nurse, two interns, and a resident. He was perceived to be medically difficult because the etiology, diagnosis, course, and appropriate treatment of his disease were uncertain. In addition, he appeared demented and this, too, was considered problematic.

Case Study 1, Mr. J.: Mr. J. was a 70-year-old former merchant marine and coast guard sailor. He looked 10 to 15 years older than his actual age. When I visited him he appeared withered and frail, disoriented and confused, but nonetheless happy and eager to talk to me. His appearance contrasted markedly with a description of him in medical notes as "vigorous" and "alert" by his long-time physician, Dr. C.

Mr. J. had a long psychiatric history of bipolar affective disorder that was controlled with lithobid, Xanax, and chloral hydrate for sleep. His background history was significant psychiatrically in that he was hospitalized in a psychiatric facility for four years during adolescence after his father killed his mother and then committed suicide. He was subsequently raised by a grandfather who sent him to military school.

On March 3, Mr. J. appeared in the ER, "ataxic and confused," shortly after spray painting some screen doors and windows in an unventilated garage with paint containing toluene and xylene. He was described in ER notes by the resident on duty as having "slow and monotone speech" and being "slow thinking." He could not stand up and was very "subdued." He was referred to as a "vague historian," though "cooperative." A neurology consult concurred that Mr. J. was

ataxic and confused and also added that he was "lethargic" and somnolent." An MRI and diagnostic and metabolic work-ups were termed unrevealing. No evidence of poisoning was found. Nonetheless, Mr. J. was given a diagnosis of "ataxia and confusion after use of Krylon spray with toluene and xylene."

Over the course of the next few days, Mr. J.'s condition deteriorated. He was described at most times as "disoriented" and "confused," but at some times by nurses as also "combative." The intern on the team assigned to his care said to me: "He's getting worse and no one knows why. We've contacted poison control but that hasn't been at all helpful." It is at this time that Mr. J. also began to be described by some providers as "demented." An intern, for example, remarked that he was "demented and cannot hold still." In order to do an MRI of his head (which required that Mr. J. hold his head perfectly still), the intern complained how Mr. J was difficult:

> I'm caught between sedating him to the point where he can be studied versus sedating him to the point where he cannot breath. So I ended up having to sedate him before [the MRI]. I had to schedule his MRI, have them call me thirty minutes before so I can sedate him, and then having to return to down to the MRI machine with him to make sure that he is sedated enough and not oversedated. It took a 15 minute chunk out of my day and I've got lots of stuff to do. [CN, male, intern]

The case of Mr. J. in many ways typifies cases of medical difficulty: He is elderly; he has a long, complex, and difficult to interpret combination of medical history and presenting symptoms that make diagnosis (and consequently) treatment and prognosis

uncertain; his disease course is uncertain and his condition worsens; and finally, there is the possibility that he is demented.

His case also raises two other important issues: (a) the important moral issue for providers of distinguishing between medically and behaviorally difficult patients; and (b) the ways in which and reasons why providers clarify uncertainty; In medical notes, Mr. J.'s attending physician, Dr. C., went out of his way to explain in very certain terms that Mr. J. was not difficult for behavioral reasons. His was definitely a case of medical, not behavioral, difficulty. He wrote: "His previous well-documented diagnosis has been bipolar affective disorder, but the patient *has never been in a state such as what I witnessed* in the ER. His maintenance medications, which he *never abuses* are chloral hydrate for sleep, Lithobid, and Xanax. Lithobid levels *have always been within therapeutic levels. He does not drink and I have never seen him in an inebriated state. His primary interests over the years have been deep-sea diving for remnants of naval vessels from the 18th and 19th centuries off the east coast of the U.S. He has a reputation of integrity, honesty, and complete dedication to this work.*

In short, Dr. C. conscientiously constructs Mr. J. as being difficult for reasons other than his behaviors and rules out difficult personality as an explanation for Mr. J's difficulties. Mr. J. is difficult, he suggests, for acute medical reasons. He specifies that Mr. J.'s bipolar disorder has been successfully managed for many years, that he has never abused his medications and is not noncompliant, that he has never used alcohol, that he has had an

accomplished career, and is of good character. The importance of these typifications is explored in depth later in the dissertation.

Summary and Conclusions

The findings presented here reflect some of the same categories of problems described earlier in current medical literature, but go quite a bit further to systematize these data. In sum, medically difficult patients (patients who providers perceived as difficult for medical reasons) represented an important source of difficulty for providers. They conceptualized medically difficult patients within five domains that included cognitive/psychiatric problems, problems of chronicity, problems of uncertainty/unpredictability, multiple medical problems, and absence of cure. Providers associated medical difficulties largely with specified groups of people. These included especially the elderly and elderly Russians, and also people with AIDS. This observation is hardly surprising given that at this institution these three groups of patients represented about 80 percent of the total inpatient population and 65 percent of the clinic population.

Providers asserted three reasons for why medically difficult patients were problematic: They reported that such patients complicated or impeded care management, were difficult to establish rapport with, and engendered negative personal feelings of helplessness and failure. Nonetheless, they rarely blamed medically difficult patients for being difficult. Because they interpreted medically difficult patients' difficulties as

unintentional, they typical regarded these patients with sympathy and care.

Endnotes

1 All percentages are rounded off to the nearest whole number.

2 The common perception among them was not that old age necessarily predicted failing mental status, but rather the converse, that failing mental status generally predicted old age. See appendix II for a complete discussion of providers' definitions of old age, Fineman 1993.

3 State policy in Russia pertaining to the emigration of Russian Jews to the U.S. stipulates that the elderly parents and grandparents of visa recipients must (in most circumstances) leave the county with their younger family members.

4 For a complete discussion of the meanings of chronic disease and old age see Appendix II, Fineman 1993.

5 The moral dimensions of chronic pain are discussed separately in a subsequent section of difficult behaviors. The separation of pain into these two discrete categories is merely a convenient analytical device. In everyday practice, providers' global assessments of patients almost always involved simultaneous moral as well as medical assessments. This was particularly true of patients with pain, for whom moral issues were virtually always raised.

6 A case observed during medical rounds illustrates the value for teaching purposes of patients with predictable disease trajectories:

Mr. F. was an 88-year-old man who was hospitalized after suffering a mild MI. Other than having cardiovascular disease, Mr. F. was in apparent good health. He was quite active physically, and looked 20 years younger than his age. He had a jovial way about him and was very well liked by members of the house staff, many of whom joked with him. The aim of this hospitalization was to stabilize Mr. F medically and evaluate him for either by-pass surgery or angioplasty.

Mr. F's EKG was unusual in that the wave cycle of an MI, which is known to be predictable, was in his case incomplete. In other words, the resident surmised that Mr. F's heart attack was not yet over because the wave cycle had not completed itself. One by one, the resident pointed out to his intern and students the pattern of EKG waves, and explained their meanings. And in doing so, he implicitly affirmed and made clear the advanced state of medical knowledge and science. [medical rounds JJ, RS, 4/20/93]

7 The problems associated with assessing the ambiguous meanings of alcoholic, drug addicted, and pain patients shed light on the moral criteria that staff members used to discriminate between intentionally and unintentionally difficult patients. Garfinkle (1967) has previously suggested that people's assessments of ambiguous meanings serve to reveal the assumptions that underlie their common sense, taken-for-granted understandings of reality. In his discussion of Agnes, a case study of a hermaphrodite, he pointed out how Agnes' sexual ambiguity served to reveal the assumptions underlying people's taken-for-granted understandings of sex and gender as being either male or female. In a similar way, the moral ambiguity of alcoholic, drug addicted, and pain

CHAPTER 5

DEFINING DIFFICULTY:
Providers Subjective Understandings of Circumstantial Difficulty

Introduction

Circumstantially difficulty patients are patients who providers consider difficult because of some specific and special circumstance of the patient's personal life or health care needs. Thus the domain does not include all patients with difficult life circumstances (for example, problematic personal, familial, or social circumstances like poverty, homelessness, marital problems, widowhood), but only those patients whose difficult life circumstances made care giving difficult to provide. Nor does the category include circumstantial problems of providers (such as overwork, being postcall, or having poor relations with other staff members) even though such circumstances, in the words of one intern "tend[ed] to make a difficult patient more difficult."

Circumstantial problems represented an important source of difficulty for doctors and nurses. Ninety-seven percent of doctors and 94 percent of nurses cited at least one factor of circumstantial difficulty that was very difficult for them, and most providers identified more than one. The number of circumstantial difficulties reported by providers ranged from 0-4. The mean was 2.2 (S. D. = 1.1.)

Providers identified six factors of circumstantial difficulty. These included (in order of the number of providers who reported them): having a difficult family (63%), being Russian (51%); lacking caregiving support (33%); needing language translation (33%), needing special or difficult to provide care or services (24%), having legal, institutional entitlement to unlimited health care when such care was deemed to be excessive or futile (21%).

For purposes of analysis, I aggregate these factors into three conceptual categories (see Table 5:1). These include, in

Table 5:1 Conceptual Categories of Circumstantial Difficulty

	Doctors N=31 providers citing yes responses	Nurses N=32 providers citing yes responses	Total Providers N=63 providers citing yes responses
Circumstances of Patients' Lives:			
having a difficult family	14	26	40
being Russian	21	11	32
lacking care support	6	15	21
Circumstances of Patients' Medical and Social Care:			
need for translators	12	9	21
need for special or difficult to provide care	6	9	15
Other Circumstances:			
legal entitlement to care	2	11	13
Totals	61	81	142

ranked order of importance, circumstances of patients' life, circumstances of patients' care, and having legal entitlement to unlimited care.

Problem Circumstances of Patients' Lives

Problem circumstances of patients' lives refer to three provider-identified but apparently unrelated characteristics of patients' personal lives, any one of which might render patients difficult: having a difficult family, being a Russian immigrant, and lacking care-giving support. One or more of these circumstances were cited by 59 providers (29 doctors and 30 nurses; representing 94% of providers) a total of 93 times (representing 65% of all citations of circumstantial difficlty).

Having a difficult family. Two-thirds of providers complained that some patients' families were a persistent source of problems for them. They considered that families were difficult for many reasons. These included being "overprotective," encouraging patients to be "overly dependent," or, alternatively, refusing to take “proper responsibility” for the care of patients; withholding crucial medical information from patients (for example, not divulging a terminal diagnosis) when such information was deemed by providers to be important for the patient to know; "challenging," "questioning," or merely failing to support a clinician's "appropriate" treatment decisions, and, therefore, in the words of one intern, "negat[ing] everything we say once [the patient] leaves the office"; supervising

or scrutinizing too closely a patient's care (a common complaint, referred to by one intern as being "meticulous"); disagreeing with one another about the diagnosis, treatment, or disposition plan, or about the provision of care, and as a result, having inconsistent care demands for the patient; having "unreasonable expectations" about the level of care provided; or, finally, threatening to sue, or actually doing so.

Providers considered that difficult families were at best nuisances and at worst adversaries who provoked feelings of anger, frustration, and helplessness.[1] The following statements typify and summarize providers' many perceptions of difficult families. In all of these reports, there is the pervasive sense that providers felt unfairly criticized--even victimized--by difficult families, and that they considered their efforts to deal with difficult family members to be futile. As one nurse lamented, "no matter what you do, it's not the right thing."

> I find patients who have family that are overprotective or overbearing, just make it difficult for me to do my job. They challenge everything that I do, question me time and time again about meds...no matter what you do it's not the right thing for their family member. [CW, female, asst. head nurse]

> They [difficult families] feel we're not doing everything possible for them [the patient]...They'll either call constantly or when they're here, say: "My dad hasn't been washed today." You say: "Well he was washed today. He's been turned. We really are trying to make keep him as comfortable as possible." And they say: 'Well I don't think so." So it's like I don't what else I can do. [EH, female, LVN]

> They're [difficult families] meticulous. They want something done in a specific way and they don't really understand what is going on and you try to do your best to describe to them but they really have a problem with what your doing. [RS, male, intern]

> Frequently you'll get quite strident demands from two different family members requesting exactly the opposite treatment for their parent or grandparent. Needless to say that's a nightmare for a physician who lacks the wisdom of Solomon to decide which family member is right. [JL, male, geriatrician]

Being Russian. On the interview handout, providers were offered the opportunity to comment on difficulties stemming from "cultural/ethnic/racial differences." Most providers responded to this item. Slightly more than half of the interviewees (51%) stated that differences between themselves and their patients in ethnicity, culture, or race were major sources of difficulty. They regarded such differences as problematic because they perceived them as barriers to providing care, or to establishing rapport.

Although difficulties stemming from cultural/ethnic/racial differences were sometimes associated with African Americans, and to a lesser degree with Hispanics and Asians (and in one case with a Jehovah Witness family that refused blood transfusions for a hemorrhaging child), when doctors and nurses in this sample spoke about cultural difference as a difficulty, overwhelmingly and uniformly they were referring to newly arrived Russian immigrants.[2] Of the 32 providers who reported cultural difference as a difficulty, 31 (97%) of them explicitly singled out Russian immigrants as the

illustrative case. I have therefore labeled this category of circumstantial difficulty "being Russian."

Russian immigrants at Mt. Sinai were notorious, legendary, and legion. Personal stories of them abounded. Among nurses, interns, residents, and attendings alike, Russian immigrants were the butt of jokes and the focus of much frustration and outrage. And no one with whom I spoke ever voiced the slightest concern about talking disparagingly about them in public or on tape. (This, of course, was not the case for other ethnic, racial, or religious minorities.[3]) For many of the providers in this study, Russian émigrés represented quintessentially difficult patients and people.

The following excerpts from four provider statements about Russian immigrants represent accurately the stories of many. Together, these excerpts underscore three striking and common themes in providers' reports: First, they convey the sense that providers perceived Russian immigrants as being difficult *people* as well as difficult *patients*; (in other words, that they were difficult people in general, not only inside the hospital or clinic). Second, they all convey the anger, certainty, and rectitude with which providers pejoratively stereotyped Russian immigrants. Third, in different ways they all express the similar sentiment that most Russian émigrés shared a number of central and defining negative qualities. Among these were being expert at "working" or "manipulating the system," or "try[ing] to trick people" in order to get “undeserved” or “unnecessary” medical services and treatments;[BG, female, RN/administrator], having "hidden agendas" or "senses of entitlement; and " being audaciously "pushy", "demanding", and

"manipulative" in the extreme in seeking what many considered to be inconsequential, trivial, or petty perquisites.[4, 5] Fourth, these excerpts often express the common sentiment (discussed in chapter 4) that Russians complained and suffered a great deal of physical pain.

> They manipulate to get things that they want. They will have you filling out forms for everything from getting transportation to getting compensation from the German government [for war crimes committed during the holocaust]. If you give one of them artificial tears for their eyes, the next month every single one that comes in needs to have artificial tears too because you gave them to one, they're entitled to it. [HB, male, geriatrician]

> I had a patient who believed he was radiated and damaged in Chernobyl. We ordered some blood tests and when he came back there were thousands of dollars worth of blood work done and I went to the slip and I found out the patient between when I gave him the form and when he submitted he had marked off all the boxes on the blood testing form and that made me very disturbed and upset. [WB, male, intern]

> [T]oday the medical nurse wanted to know if we could take this patient in eye clinic. [T]he doctor's on call and he's willing to see these drop-in patients. We drop this lady in and she and the helper that was with her said "Well we have to be somewhere for 12:00." The lady just kept jumping out of the chair before the doctor was really finished and she kept pushing me to get to move things along when I couldn't...So I got very annoyed with her. I felt that we did our best to get her into the clinic, we got her a full exam so she wouldn't have to come back here which meant that I was going to get out the clinic late, the doctor may get out late. [JP, female, nurse]

> "They (Russians) are not successful at what they're doing. They're successful in gaining these things that they want but they are failing miserably in terms of earning respect and

> goodwill...I've talked to enough nurses that I'm involved with here in the hospital to validify my feelings that it's not just, I'm not stereotyping them, they actually are this way." [GM, female, RN] [6, 7]

Lack of caregiving support. Lack of caregiving support refers to the problem of many patients, especially those in late life, who are without family or friends to care for them at home or lack the financial resources required to hire aides or home workers. Both of these situations created management problems for providers regarding patients' disposition and continuity of care.[8] Twenty one providers (15 of whom were nurses) cited lack of caregiving support as an important difficult circumstance of patients' lives.

Provider difficulties brought about by patients who lacked caregiving support included: (a) threats of case reviews and law suits; (b) the need of these patients for lengthy and "unnecessary" hospitalizations even after they were medically stable, in order to care "merely" for their social needs, (c) the large amount of time these patients consumed, and (d) the necessity of providers to assume responsibility for these patients, many of whom they resented. These problems were summed up by a geriatrician in a grand rounds presentation, and by a nurse.

> [A] situation that we see time and time again is that we will admit the patient with an acute illness, and the next morning we will realize that, wait a second, this person cannot possibly go home to their previous living situation. What was, in essence, a simple admission, perhaps for dehydration or something, becomes that bane of our existence: the disposition problem!...A classic situation is where the patient is doing great; they are recovering from their pneumonia, everything

> seems to be getting ready, and you start saying, "well it looks like tomorrow, we might think about you going home," All of a sudden, "Oh no, I can't possibly go home, I can't take care of myself..." and a crisis hits. Another one that has happened to me on several occasions is that everything goes swimmingly for the whole hospitalization. The patient gets home and they cannot walk, or they cannot care for themselves. You get a frantic call immediately after discharge. Needless to say, the last thing you want to do is immediately readmit them, which is an automatic trigger for review of the case, so that calls into being a crisis management situation, and of course, the last situation you want to hear from is when you hear from the lawyer. [JL, male, attending geriatrician]

> Before, we could have patients for four days or a week, [and then] they would go home. Now, it seems difficult because we will be staying with them like two weeks to find them a place, because they have no relatives, they're just on their own, they just take all our time. So that's what makes them have more difficulties than before. [R, female, RN]

Circumstantial Problems of Patients' Care

Problematic care circumstances refer to the organizational and institutional problems that some patients' care needs necessarily incur, reveal, or exacerbate. These circumstances included the need to use translators, the need to provide special or difficult to provide care, and the need to provide legally mandated care to patients who providers felt were not entitled to it. Circumstantial problems of care were cited by 31 providers (16 doctors, 15 nurses; representing 49% of providers) a total of 49 times (representing 35% of all "citations of circumstantial difficulty.

Need for translation. Although a substantial minority (13%) disagreed,[9] many providers (33%) felt that the need for translators was a source of significant difficulty. Not surprisingly, provision of translation services was often associated with Russian patients.

Providers felt that use of translators was problematic for a number of reasons. First, they reported that translation of their interactions with patients consumed a great deal of their time, a problem that was exacerbated by a shortage of competent translators. Second, even though they acknowledged that the hospital translators worked very hard, they complained that there was often a wait for them to arrive. Third, they complained that the translators were in a rush to leave. "The interpreters are very busy here," an intern remarked. "You can see it. [T]hey will definitely ask you if you've finished your questions, so there's a time pressure there for them as well as time pressure on me because often I've got to go see other patients. [RS, male, intern] [10]

But the real difficulty underlying the use of translators was providers' perception that it created a breakdown in communication between themselves and patients, and that ultimately, it was an impediment to establishing rapport with patients. Three providers commented:

> ...[S]ometimes even if we do have a Russian translator, it seems that it is not all communicated very well or something is lost in the communication process. [EL, female nurse]
>
> The fact that I can't talk to them is difficult. It's hard to get past that...I don't know how many times I will try to interview these patients through an interpreter and I know just from the

> answers that I get back that there is something missing....[KS, female, intern]

> It is difficult to take care of people when you can't communicate...when there's a communication breakdown there's going to be some bad relationships. [AY, female, LVN]

Need for special or difficult to provide services. About a quarter of providers believed that the hospital was not organized to deal with certain patients' specialized care needs, a situation that created a host of difficulties for providers. These care needs were diverse and included such services as special or intensive nursing care outside of the ICU, long-term care in-hospital, and requests for unavailable equipment. One resident commented, "The system isn't really set up to anticipate or provide the needs you feel are important for the patient. [For example], if you're asking more specifically, [one problem is] getting patients appropriate longer term care. [MM, female, resident]

Two brief examples illustrate the kind of problems encountered by providers whose patients required difficult to provide services. They also illustrate the degree of anger that these cases could provoke, anger directed not at the patient, but rather at the source of difficulty--which in both cases was the hospital bureaucracy. In both cases, the issues underlying physicians' anger were their perceived loss of authority and sense of powerlessness. In the first case, an intern fumed because the hospital wouldn't provide round-the-clock nursing care for a patient who she thought

needed it. In the second, a doctor's request for an air mattress caused great difficulty.

Example 1: In this example, an intern became angry because she was powerless to order 24-hour nursing care (outside of the ICU) for a patient that she believed was in potential danger. She also reported feeling frustrated and demeaned by having to perform what she called a "baby-sit[ting] task," a task that she considered was not doing "medicine."

> A couple of nights ago I had this fellow that...need[ed] to go to the [ICU] unit. I thought that he was going to be a problem. I called the unit right away. But just because the man was no problem then, they sat on it for awhile. I baby-sat the man until three o'clock in the morning. [There] wasn't any medicine that I needed to do. He need[ed] to be in a place where he [could] be watched. And when you're night floating, you have a whole hospital to take care of and I [did] not have time to be baby-sit one patient like I had to do that night. I was furious. It was just totally inappropriate. [KS, female, intern]

Example 2: In this example, a resident was angered by his inability to order for a patient a mundane but (he thought) essential item, an air mattress. He specifically framed the issue as one of his perceived loss of authority.

> We have a terminal patient that we saw this morning with cancer, who is totally obese and is a big set-up for bed sores, pressure on her skin, breakdown; she'll get big sores. That's the last thing you want. She is too big to move and she doesn't have an air mattress. It was Sunday and I wrote [an order] for an air mattress [in her chart]. The nurse came back and said, 'You know, they said that they can't get you an air mattress. It needs to have skin care nurse approval and she is not here

> today.' Immediately I was like, 'What the fuck are you telling me.' You catch yourself saying, 'I am the physician.' I said 'She needs an air mattress and goddamn it, I want one. I know they have them here, I don't need no friggin' skin nurse to tell me who needs an air mattress. I am a physician. I am more educated. It is my ultimate responsibility for the patient's care.' I was just so pissed. Not at the nurse, she just passed the message, but I was fuming inside...They challenged my authority and my discretion on my own patient's care, what was needed, and what I felt was best for the patient...It pissed me off because I felt that challenge and the loss of control and authority...It was ridiculous that I was being told that I couldn't do something when people less trained than me were going to make the ultimate decision. [GC, male, resident]

Legal entitlement to "undeserved" care. Thirteen providers reported that patients who had legal entitlement to unlimited health care were difficult for them if they deemed that such care was undeserved. Most providers who identified such patients as being difficult were angered by the fact that provision of health care to this group necessarily deprived others of deserved care. This category applied mostly to Russian immigrants, who by virtue of a contract between Mt. Sinai and Jewish Family Services, received unlimited and free in-patient and out-patient care at the hospital. It two cases, it was also applied to the elderly, especially the demented elderly. One physician, for example, commented

> It kills me to send ninety-four-year-old patients who haven't been out of bed in three years and don't know what city they're in to a type of care unit for multiple tens of thousands of dollars in therapy when the kids in Hunter's Point don't have textbooks. And that for me is a constant and recurrent issue in the hospital. I think those are also difficult patients for me. [SB, male, resident]

The following reports all illustrate providers' anger towards Russians for having unlimited and free health care.

> I feel that for the most part these are immigrants who were not oppressed where they came from and have tremendous expectations for things here that the average American doesn't get. And this tremendous arrogance that I don't feel from other people. It's really troublesome to me. [LK, female, attending]

> Why should they get MediCal to begin with where people in this country may deserve it and not get it. These people get it right away and they're foreigners. [K, female, RN]

> They all wait until they get off the plane and then they fall over; they save up their thirty years of heart disease until they step on California soil. Look at what all the Russians get. They all get everything and look at the unemployment in this state. They get plugged into social service programs, they may be able to get taxi vouchers home because they're not able to take the bus, they get plugged into housing. They get hooked into all kinds of systems. [MM, female, RN]

> [When] the Russian immigrants come, someone brings the tour bus by here and tells them that placing your hands over your heart and saying it's the big one is the sure entrance for Mount Sinai Hospital. Somebody probably told them that they're only covered for a short time by MediCal and when they get into the country, anything that's bothering them [they should] get in and have it taken care of. [GM, female, RN]

> I feel that when you come to a new society there's an adjustment on both parts. There comes a point when the system needs to be understood and I think these people have learned (it's almost like a neurotic obsession) to get as much as they can of everything whether they want it or need it....I just don't like that. I don't like that in people, I don't like that in groups of people....I don't like people that don't have their own sense of responsibility about doing for themselves and I

> also feel there's scarcity of resources and I think that this group of patients generally is using up a lot of resources. I personally think new immigrants should be entitled to free health insurance, I think it's good for society in general. But I don't think it should be limitless, I don't think it should be endless and I see that happening. It's really grating to see it all the time. [EM, female, RN]

In sum, circumstantially difficult patients were considered difficult by providers because of some special characteristic of their personal life or of their care needs. Among these were having a difficult family, being Russian, lacking caregiving support, needing language translation, needing a special or difficult to provide service or medical item, and having legal entitlement to unlimited care. As with characteristics of medical difficulty, providers of this hospital often associated characteristics of circumstantial difficulty to elderly people, Russians, and less often, persons with AIDS.

A Case of Circumstantial Difficulty:

The case of Mrs. M. illustrates well many of the defining characteristics of circumstantially difficult patients: She was a recently arrived elderly Russian émigré and spoke no English; she had a difficult family who were seen to be unwilling to care for her out of the hospital, a circumstance that created disposition problems; and she was legally entitled to receive care that some providers thought was undeserved, which made them angry. Secondarily, Mrs. M. also was considered medically difficult by some

providers because she was seen as possibly demented. Most of the doctors and nurses who cared for Mrs. M carried on a running dialogue whether she was demented or just impossible to get along with.[11] She was identified as difficult by 10 providers including two residents, four interns, two nurses, a utilization review nurse, and a social worker.

Case Study, Mrs. M: Mrs. M. was a 71-year-old Russian immigrant who recently arrived in the U.S. with her son and daughter and their families. She was admitted to the hospital in March with a diagnosis of cardiac arrhythmia and altered mental status, and again in April because of chest pains. Admission records from the March admission noted that until two days before she had been in her "usual compensated health" and then suddenly experienced weakness, and confusion. When she did not recognize her family, they took her to the ER.

Mrs. M. had a history of hypertensive cardiovascular disease, diabetes, and possible coronary artery disease. Upon admission, she refused angiographic evaluation and Persantine thallium imaging. Although she had no prior history of psychiatric problems or dementia, when seen in the emergency room she was thought to be "agitated," "combative," and "disoriented," and was described by a physician as "not making any coherent sense. Admission records noted a change in her mental status and commented that "the etiology of the change is unclear, but hypertensive encephalopathy is conjectured." Subsequently, during the first week of her hospitalization, Mrs. M. was variously referred to as "babbling,"

"crazy," "confused," "very physically aggressive," "uncooperative," and "noncompliant." Nursing staff in particular complained that she "refused to take her meds," "pulled out her IV," and sometimes punched, kicked, and tried to bite them. One referred to her as "a wild woman." When a Russian neurologist tried to examine her, she screamed "Let me go, let me go!"

Although Mrs. M. was also deemed to be difficult for medical and behavioral reasons, she was perceived as difficult principally for circumstantial reasons relating to her difficult life and care circumstances. Fundamentally, Mrs. M. was seen as a difficult patient because her family was perceived to be difficult. At the heart of the problem were Mrs. M.'s children, who, according to many providers, refused to care for her at home, had unreasonable expectations about her care in the hospital, and insisted that after the hospitalization she be placed in a nursing home. As one physician observed

> [The difficulty] was more with the family and dealing with them and their expectations and what her care should be like [and] what they wanted from the hospital, which was different from what we were set up to give them. They wanted her to be able to be cared for 24 hours a day and didn't want to take her home. [GC, male, resident]

This situation created very real care and disposition problems, especially for the nursing staff, the case worker, and the unit's utilization review nurse. The problem, one nursing administrator explained to me was that "Mrs. M is special because we had to find a psych unit, [and] not only a psych unit but an elderly unit for psych

patients...and [to] finally get a place, it will take us like a month or more to really get the place."

After many weeks and much effort, the social worker was finally able to secure Mrs. M. a bed in a good nursing facility. A delicate problem remained, however, because the only facility she could find was an hour's drive away, giving the family reasonable (and legal) grounds to refuse the placement. The social worker and utilization reviewer discussed this problem and hatched a plan:

S.W. M.'s daughter did not object.

U.R. Great! Now am I getting in trouble if I document this?

S.W. No. She's gonna go.

U.R. Where is she going?

S.W. Pinecrest. (a pseudonym)

U.R. It's a nice place. Do you think that [the daughter] understands that she can....

S.W. I didn't get into that she can refuse.

U.R. That's good.

S.W. The truth is that most of the Russians know that they have the right to refuse to travel that far. I'm not telling them because...it's for them to find out.

U.R. Yeah, yeah.

S.W. And her daughter has a car and is able-bodied.

U.R. I think that you've done her a service.

Mrs. M's lengthy hospitalization while she awaited placement was expensive and required a lot of services and care. Because she was a Russian immigrant, she was entitled to this care without charge, an entitlement that some providers thought--given her family's unwillingness to care for her--was neither necessary nor deserved. This made them angry. Anger and outrage about the entitlement of Russian patients to "unlimited" care was most vociferously voiced by the utilization review nurse who handled Mrs. M.'s case. She summed up her feelings in a brief diatribe:

> [T]here's a scarcity of resources and I think that this group of patients generally [Russians] is using up a lot of resources because of their manipulative behavior...This is the reason I personally don't like dealing with their charts sometimes...There's so much dysfunctional behavior around to give care to these people on everyone's part...There's an attitude of maximum care, maximum care, maximum care. It's almost like an automatic behavior. I personally don't believe that maximum care for people is the way to always go and I also think it's incredibly expensive. I personally think that new immigrants should be entitled to free health insurance. But I don't think it should be limitless, and I see that happening. Mrs. M. is an example. The family just won't take her home. They wont' take her home on a trial, they won't accept the kind of health support that they could get for her. They just decided that she is not their responsibility, she's ours. So I really do feel angry....[EM, female, RN/utilization reviewer]

And while providers' anger and blame were not directed at Mrs. M. herself (such negative feelings were, instead, directed at the children, who were perceived to be the direct cause of the problem "She," as one physician observed, "was not the difficult patient because she couldn't really help what she had--a medical condition that was beyond her control...I don't put the blame on her."), Mrs. M. nonetheless bore the brunt of some responsibility for "causing" the whole situation in the first place and for being the recipient of all the unearned gains. A remark by the social worker is illustrative. Upon learning that Mrs. M. was back in the hospital (but in the nursing unit, not on the general medical floor where she was previously) the social worker responded, "That's just fine as long as she stays there and doesn't come back [here] because she caused enough problems. [AG, female, social worker]

Summary and Conclusions

In sum, circumstantially difficult patients were an important source of difficulty for providers. They conceptualized three domains of circumstantial difficlty, which consisted of six kinds of difficulty: having a difficult family; being Russian; lacking care support; need for translators; need for special or difficult to provide care, and legal entitlement to care that providers viewed as undeserved. As with characteristics of medical difficulty, providers often associated characteristics of circumstantial difficulty with particular groups of people, namely elderly people and especially Russian émigrés.

As with medically difficult patients, providers reported that circumstantially difficult patients were problematic because they complicated or impeded delivery and management of care, and because they engendered negative personal feelings among providers. But in contrast to medically difficult patients, circumstantially

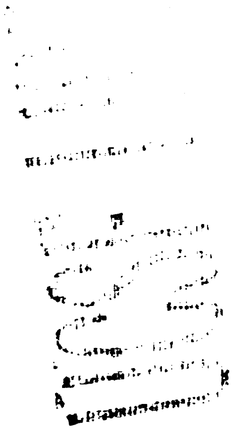
difficult patients engendered not only feelings of frustration and helplessness, but feelings of anger as well. In particular, nurses, but more often doctors, expressed outrage and anger towards difficult family members, Russian patients whose behaviors they viewed as manipulative and demanding, and intransigent hospital bureaucracy. A common theme among providers' reports of becoming angry was their threatened sense of authority and empowerment. I develop this theme later on in the dissertation.

Endnotes

1 The following two stories dramatically illustrate the depth of anger, frustration, and hostility that difficult families could generate. The first story, told by an intern, concerns a mundane event gone awry; the second story, by an attending physician, represents an extreme case that he presented as a "difficult family nightmare."

> A patient was having a GI study done because he had some GI bleeding and it was explained to him that he wouldn't be able to eat until his study was completed. His study was completed at 1:30 and he had to have an additional X-ray taken at 2:00. The X-ray tech got to the floor and took the X-ray at 2:15 and by the time the portable people got down to the X-ray department it was quarter to three. I had just read his films and told him he could eat. In the meantime he called his entire family in so they could yell at us for not allowing their poor family member to eat. He is a cardiac patient and he got so upset that he started having chest pains and he was having an angina attack. They're screaming at me, he's sitting on the bed gasping for breath and clutching his chest, and I'm having to explain to these people it takes longer than two or three minutes [to do an X-ray]...It's frustrating for me to run into that. I'm angry that I got yelled at...I just feel that nobody is supposed to like yell and scream and act like a child, especially an entire family. They're entitled to a certain degree of irrational behavior, but I just hate to be yelled at. I was never yelled at. I've never been yelled at in my life. I've never even heard my father raise his voice. [CN, male, intern,]

> They [difficult families] ask you for things you can't possibly deliver and then blame you for not delivering. That's' a common trick. Once gentlemen blamed me for not finding his mother's cancer [even though] I had been pleading with him for over a year to get a CT scan because I was convinced there was some kind of malignancy there. The only question was what kind of malignancy. I had narrowed it down to a few choices where a CT scan would easily solve the problem. We have documented evidence in the chart that they were asking him and pleading with him to get this thing. Finally, what worked is that I said "If you don't get this



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> scan, I don't see your mother anymore. Period! End of discussion! No negotiation here." They got it and it showed a big tumor which unfortunately at the time it showed up was no longer curable and she died of it. Then he went ahead and was talking about suing me for failing to describe it, stating that I should have gotten a Russian interpreter because they would have understood better the need for a CT scan. I pointed out to him that he is a registered nurse in this country and he understood what a CT scan was and that [his case] was total nonsense. [AH, male, attending]

2 Providers in this hospital made no secret of their sentiments about Russian patients. They openly shared their notions and feelings about Russian patients among themselves, with me, and in front of Russian translators, nurses, and physicians. To some extent, acculturated Russian staff members aided and abetted stereotypic representations of Russian immigrants by acknowledging their truth and accounting for them with the same explanations as given to me by providers. Perhaps because such information came from Russians themselves, did providers feel free to openly voice their biases with such enthusiasm and conviction. Why there was no reluctance to talk about Russians remains a mystery to me.

This portrait of Russian émigrés as difficult was confirmed by a Russian physician who agreed with the American providers that Russian patients were indeed difficult as a result of cultural differences. But she made the critical distinction of finding American, not Russian culture at the heart of the problem:

> They were not like this in Russia. Just here, It's the system here and their circumstances that make them this way...They all come in [to the clinic] for secondary gain. They're 55 or older and speak no English. They can't work...What can they do? They come here and they can't do anything. They may have been accountants or skilled people in Russia but here they can't do anything. They aren't going to learn the language and they can't get jobs. So in order for them to get public assistance they have to lie. And how do they lie? They have friends who have moved here previously and tell them how to do it. That's how. They all have the same story. They all complain about back pain, neck pain, chest pain; I can predict what they'll say before I see them. [MK, female, attending neurologist]

3 Very few providers openly acknowledged other ethnic or racial groups as being difficult. This is hardly surprising given their level of education, their ethnic, racial, and cultural diversity, and the stigma among them of being identified as a racist. However, a few providers did acknowledge that they were often suspicious of young Black and Hispanic men who requested analgesics. They believed that many such patients used the clinic to elicit illegal drugs. Two nurses also identified Asians as being difficult.

4 This is a Jewish character type commonly known in Yiddish as the *schnorrer* (pronounced like snorer). Rosten (1968) defines a schnorrer as a beggar, a moocher, a compulsive bargainer. He writes:

> Every Jewish community once had at least one schnorer, and often a platoon. The schnorrer was not a run-of-the-mill mendicant. He was no more an ordinary mooch than a nudnik is an ordinary bore. The Jewish schnorrer was not apologetic; he did not fawn or whine. He regarded himself as a craftsman, a professional. He did not so much ask for alms as claim them. Schnorrers...were brash, cynical, quick to take offense, expert in needling prospective benefactors, and quick in repartee. Their *chutzpa* was of a rare and umbrageous order. They often baited their benefactors, haggled over the sum proffered, denounced those who underpaid or refused to cough up...On the part of the Jewish community,

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> schnorrers were somehow regarded as performing a social function. Exactly what this function was, I could never fathom....

A groaningly painful example from Rosten illustrates the "hauteur of schnorrers:"

> A schnorrer came to the back door on the biweekly rounds. "I haven't a penny in the house," apologized the *baleboosteh* [a praiseworthy homemaker]. "Come back tomorrow." "Tomorrow," frowned the schnorrer. "Lady, don't let it happen again. I've lost a fortune extending credit." [Rosten 1968:364-368]

5 Although providers perceived Russian patients to be manipulative, pushy, and obnoxious in myriad ways, the root causes of their difficulty were perceived to be essentially two: Number one, they were difficult because they had been socialized into a dysfunctional culture (Soviet) that propagated social and medical values and practices incompatible with those in the U.S. And number two, Russians were difficult because they did not understand American social and medical values and practices and hence did not understand how to appropriately think and behave in America. In short, Russians were difficult specifically because they were not American and especially because they were Russian. They were viewed as very different from Americans. As one resident said "We're getting people at the age of sixty-five who spent their entire life in a different medical model that doesn't fit ours" [SB, male, resident]. Many providers agreed:

> The Russian patients that we see [have a] totally different mindset about what medicine is and how a doctor should treat you....[JR, female, attending]
>
> [T]hey have a different view of how medicine's practiced. [RS, male, intern]
>
> Their whole concept of the medical system is very different from ours...They don't have the same meds and the whole mindset for treating a lot of diseases is completely different. [LT, female, intern]

The explanation that Russians were difficult because they were not socialized into American society or medicine was "known" by most everyone. Of those providers who identified Russians as being difficult, fully 77 percent specified that the reason Russians were difficult was that they did not understand American culture in general and American medicine in particular.

What precisely was wrong with Soviet culture and the Soviet medical system and how did these wrongs foster difficulty? Providers affirmed that the Russian medical system was inaccessible, unsophisticated, low-tech, impersonal, bureaucratic, and altogether inferior to that of the U.S. It was held to be a system that didn't properly understand chronic disease or its treatment, that was overly secretive and hence did not value the importance of properly informing patients of their diseases, especially terminal diseases, that was wholly unfamiliar with many types of technology in common use in the U.S., and most importantly, that uniformly bred somaticizing and dependence, and rewarded aggressive, manipulative, demanding, and complaining patient behavior.

Providers enumerated a list of commonly assumed deficiencies of Soviet medicine and society, each of which was held to underlie numerous patient difficulties:

(a) Soviet medicine is inaccessible. Providers believed that quality health care was largely inaccessible in Russia. "Healthcare, a resident noted, is not easy to come by in the Soviet Union." [CH, male, chief resident] It is difficult to make an appointment and be seen and "[i]n addition," an intern said, "when they finally do get to see someone, they often have to go through three or four physicians' assistants before they actually see a

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physician." [JR, male, intern] The effect of this practice, providers believed, was that Russians didn't "understand the protocols of care in the U.S., for example, that interns and residents are competent, and therefore inappropriately demand[ed] the services of specialists." [MS, male, intern] Remarked another, "A lot of times on their initial visit, they often demand to see a neurologist or a GI specialist because they think since you're the first person they see, you must not know anything. That in itself can be difficult. [JR, male, intern] And another added, "It's very difficult to deal with when you're the doctor because they come in and say 'I want to go to ENT' [when] I haven't decided whether [they] need to go to the ENT person or not. [LT, female, intern]

(b) Soviet medicine is bureaucratic. Providers commonly presumed that gaining care in the former Soviet Union was a bureaucratic tangle that necessitated that patients, in order to get the attention of practitioners, routinely vocalized complaints loudly and persistently and learned to play the system expertly--to, in the words of one intern, "beg and demand and complain and cry and moan" [CN, male, intern] Three physicians elaborated

> I know it's a matter of having to have been manipulative and grabbing probably all their lives to survive in the old country, I'm sure that's it." [GM, female, RN]
>
> I would say that a significant portion of the Russian population is both extremely demanding and very willing to complain about everything. I think, the cultural situation in the system in order to get any care at all you had to make a lot of noise about a lot of things. So their system trains them to function in a dysfunctional way for our system. [CM, female, attending]
>
> Yeah, I think that the whole cultural situation in Russia a lot of these people, it seems like if they wanted to get medical care they had to bitch and complain about everything in a major way and yell and scream and be the squeakiest wheel to get anything. And that here, that's different.... [JR, female, attending]

(c) Soviet medicine is secretive. Many providers expressed the belief that Soviet medicine withheld information about terminal prognoses, cancer in particular, thereby making difficult the gaining of informed consent. This view was confirmed by a Russian physician who remarked:

> In Russian medical facilities, you never tell people [they] have illnesses which cause death...It's really difficult for Russian people to accept truth about illnesses here. They think if doctor told me I have a cancer, it means maybe he doesn't want to treat me because I have cancer of the throat. It means I have to die. It's very difficult. [BR, male, attending Russian]

(d) Soviet medicine doesn't appropriately understand or treat chronic disease. As previously discussed, providers often reported that Russian medicine understood neither the concept nor the treatment of chronic disease. Russian patients therefore, did not properly understand it either. They were as a consequence often noncompliant with medical regimens.

> They often take, for example, hypertension medications as p.r.n. medications--as-needed medications--rather than every day. They don't understand the importance of continuing a regular regimen. [CN, male, intern]

> They believe that when you feel like your blood pressure is up you're supposed to take a pill. I don't know how they expect people to figure out that their blood pressure is really up without taking their blood pressure. They don't believe in the daily medication thing. [LT, female, intern]

(e) Soviet medicine is unscientific. Some providers expressed the belief that Russian medicine was typified by (from a Western biomedical perspective) unorthodox, strange--even nutty--beliefs about disease origins and treatments, beliefs that were shared by Russian patients. These included, for example, the belief that negative ions in the atmosphere caused otherwise unexplainable vague bodily pains, that valerian root could treat hypertension, or that "a simple cold germ [could] kill them " [BR, male, RN]. Russian patients as a consequence often continued to rely on unorthodox Russian treatments (despite the protests of American doctors), treatments that American providers assessed to be worthless or even dangerous. As one intern told me in exasperation:

> They don't let go of the Russian medicine. It takes an awful lot of energy and time to train to get them to please throw their Valerian rig down the toilet. God only knows what they're getting when they take it. [LT, female, intern]

(f) Soviet medicine is technologically unsophisticated. Many providers believed that Russian medicine was technologically inferior and didn't have access to powerful and effective high-tech diagnostics and treatments in common use in the U.S. The presumed effect of this deficiency was that Russian patients were technologically uninformed and did not understand the benefits and risks of such procedures. As a result, they often misunderstood or refused appropriate procedures and treatments based on groundless fears or else had unreasonably high expectations of the efficacy of American medicine.

> I can't say how many times someone has come in and been very dramatic about their chest pain and they go to the cardiac cath lab and have a fit on the table...[because] they weren't expecting to get the most high-tech procedure available and they didn't have an understanding that it could be very dangerous. So I think that's a source of great frustration, that isn't understood. [JR, female, attending]

> They want you to fix the leg pain they've had with thrombophlebitis thirty years ago which they've had constantly for the last thirty years....They want you to suddenly fix the headaches they get from a head injury sixteen years ago. I've had people complain of headaches they got from World War II, like shrapnel injuries, and they think that suddenly they're going to come to America and ask me to fix their shrapnel injury headache from 1940. I don't know if they really are just trying to see if maybe there's something we can offer that they haven't seen before or whether they really think that we are going to help to fix it or whether they're just kind of bringing it up. [LT, female, intern]

> A lot of them are intelligent enough to listen but they won't let certain subjects be approached. The easiest one is there is a certain test for heart, it's called the Persantine thallium and they've heard that Persantine is bad and that it will kill you. It's done for patients who aren't well enough to exercise on a treadmill to get a treadmill thallium test. The Persantine is injected and it will sometimes cause the patient to have chest pain, which can be reversed very rapidly. But the Russian patients have within their community the myth that Persantine will kill you. So they'll refuse the test which may save their life....The minute you say

> Persantine they say no. It's the same as the kid that puts his hands over his ears. [CN, male, intern]

(g) Russian culture values dramatic suffering. Many providers stated that Russian patients presented disease and pain vividly and dramatically, waiving their hands, raising their voices, gesticulating wildly. This they believed was a culture-based style of communication that was also literally embodied by Russians who were known to commonly somaticized disease. "A lot of the Russians, they want to have pain. It's cultural," an intern told me. [WB, male, intern] Doctors reported that the difficulty of such demonstrations was that they made it difficult for them to sort out "real" pathology from "just complaining". (add a few sentences about pain, TBB, check notes. This was an essential quality of being Russian ?)

> This culture has a lot of stuff around somaticizing which kind of feeds right into the frustrations that the interns already have, [JR, female, attending]

> Cultural factors about the Russians make them difficult. They are positive for everything. If you ask them if they have chest pains, they say "yes." If you ask them if they have headaches, they say "yes." [HB, male, geriatrician]

> ...[S]ome of those people are very difficult to try to treat. You can't figure out what is going wrong with them. Somebody was saying the other day, not a very kind remark, that of 100% of the Russian patients that have chest pain, only 50% of them actually have cardiac problems and you really need to figure which ones are which and sometimes its not very easy to do. [JB, female, intern]

> The Russian patients come in and give you a long list of complaints and a lot of them don't make sense...You get people coming in saying that they have chest pain five or six times a day. You say, How long have you had this?" and they say, "Fifteen years." It doesn't really make sense of course. Although then you can go off and pursue a GI cause. It's obviously not their heart. Russian patients tend to be a little more fixated on the heart as the cause of their ailments. I think it's where they focus their angst too. ...I'll listen to their complaints of chest pain and it will sound a lot more gastric and I say this doesn't sound like there is something wrong with your heart. It sounds like something gastric. We'll give you Maalox. I figure the average American patient would probably say oh, that's great, there's nothing wrong with my heart? The average Russian patient seems a little disappointed, you know. Oh, I don't have a serious illness? [MS, male, intern]

6 I include here these additional reports by providers to highlight the ways in which Russian immigrants were perceived to manipulate to get what they wanted, and also to focus on the depth of outrage, anger, and certainty with which many providers spoke of them.

> It's a very difficult group of people to deal with. You feel ripped off when you deal with them...I've noticed across the street where I buy my coffee--a little café in the courtyard--there are benches there and the café puts out the tables and chairs and in the last few months this population has discovered, "Well here's a free place to sit." And I've noticed a few times the owners of the place, who are Korean (now why should they know prejudice?) are very cold to these people because they don't buy anything. He may go and say "You have to buy something." They may buy a cup of coffee and sit for two hours. It's not the way most people

> are and he of course feels that his business is being affected. I happened to eat lunch there today and there were like eight--I knew that they were Russian, I just knew by looking at them--and they were sitting on the benches, nothing to eat. One mother bought a little bottle of something for her child and she was upset because there was no table for her to sit at. And you know for a dollar purchase...I don't know why it is, but it seems like they incur the dislike of the people they come in contact with. [ME, female, RN]
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> A friend was telling me that over at the Jewish Community Center there were a bunch of them (Russians) waiting to get into the swimming pool and so to be nice he opened the door five minutes early. The next day, fifteen minutes early, they were there and they were saying: "You opened five minutes early yesterday...." In other words give them an inch and they assume the inch and want more...And they only notice you if you can give them something. They don't notice you unless you stand in their way...They push everyone's buttons. [EM, female, RN]

7 Of course not all providers singled out Russians (or any group of people for that matter) for special criticism. They acknowledged that although Russians were commonly stereotyped and disparaged, they, themselves, did not do so. The comments of an attending geriatrician best articulated this alternative view.

> Across the street, everyone knows the Russian patients are very difficult. I have difficult Russian patients and I have wonderful Russian patients. I don't think that any particular group is more likely to be difficult. The Russian patients have a coincidence of having come from a very different health system. In general they are on MediCal so that adds an element of difficulty and then there's a language barrier. So since there are those coexisting factors that can contribute to somebody being difficult, it may seem like there are more difficult Russian patients, but I don't really think that there is anything inherently more difficult about them. [JL, male, attending geriatrician]

8 Although providers recognized that these problems often stemmed from the broad social, economic, or demographic circumstances of American society, they nonetheless perceived the difficulties they created as being more about individual patients than about society in general. The problem was described by a head nurse in the following report:

> I think times are more difficult than they used to be and I think the difficulties people have with coping are directly related to that...People don't have the same resources that even 20 years ago people had for family resources. There's a lot more elderly people who can't get by on the incomes that they have who maybe don't have children around to help them or if they have children around to help them, their children are single parents struggling themselves to get by. There's just not the same support, psychological and physical support for people. So in that way probably difficult patients are somehow directly related to the whole cultural thing. [MM, female, RN]
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> ...[O]ne of the reasons why I think patients are difficult...is because [we] are required by society to take responsibility for problems that no other part of society wants. We have homeless people [who] come in sick and we take care of their medical problems for as long as they need it taken care of...I think they're entitled to five days of housing. But if [they] have ulcers on your leg after five days, what are you going to do? So one thing is partially some of the things have gotten harder because the rest of our society has real problems. [EM, female, RN]

9 As mentioned earlier, some providers explicitly believed the use of translators not to be a problem. Because they represented a substantial minority, I note their opinions here.

> Actually, the only thing that is difficult is because you haven't had the interpreter there. Once the interpreter comes in, to me it's not difficult because we can communicate. [R, female, RN]
>
> I don't find non-English speaking patients that difficult...because the translators are real easy to get a hold of. There are lots of nurses, especially with our Russian population, that are able to translate and family members come in and they're usually able to translate. [CW, female, RN]

10 Providers sometimes resorted to the use of family members as translators. But this brought about another set of problems. As one physician commented, "...[I]f you're forced to rely on family members as translators, that can bring in a whole litany of intrafamily conflicts that can really be a problem. [JL, male, attending]

11 Mrs. M.'s attending physician ultimately determined that she was not demented. Her agitation and combativeness, he surmised, were probably the result of missing her diabetes meds at home (causing hyperglycemia) compounded by her family's and the hospital's attempts to restrain her with a posy while hospitalized. Her confusion and disorientation were probably caused in large part by Ativan, which was prescribed in the hospital to sedate her. Two days after the Ativan and physical restraints were withdrawn, she was described in medical notes as "much better, more cooperative, and less disoriented...She has rehabilitated well, is walking daily and has become more social and friendly.

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CHAPTER 6

DEFINING DIFFICULTY:
Providers' Subjective Understandings of Difficult Patients-
Behavioral Difficulty

Introduction

Behaviorally difficult patients refer to patients who, as a result of exhibiting one or more problem behaviors, are considered by providers to be difficult. These patients represented by far the most important source of difficulty for providers. As shown in Table II:2a, page 111, providers' citations of behavioral difficulty accounted for almost t1 all difficulties. Virtually all (95%) providers identified at least one factor of behavioral difficulty that was very difficult for them, and most identified more than one. The mean number of behavioral difficulties reported by providers was 7.4 (s.d. = 4.5), more than three times the mean number of medical or circumstantial difficulties they reported; And some providers reported as many as 18 (range = 0-18), more than double the number of factors reported for medical difficulties, and more than four times that reported for circumstantial difficulties.

What were the patient behaviors that providers perceived as being difficult? Providers identified 28 difficult behaviors (see Table II:1, page 106). For purposes of analysis, I have aggregated these into eight conceptual categories of difficult behavior. These are reported below in Table 6:1 and include (ranked in order of the percentag

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percentage of providers who reported them): obstructive behaviors (81%); manipulative behaviors (73%); abusive behaviors (63%); challenging behaviors (62%); attention-seeking behaviors (49%) crazy-making behaviors (37%); irresponsible behaviors (30%); and ingratitude (17%).

Obstructive Behaviors

Obstructive behaviors are behaviors that directly obstructed or thwarted providers' efforts to help, heal, and care for patients. The central and definitive obstructive behavior was "lack of cooperation," which most providers defined as a patient's "refusal" to "listen" or "agree" to their suggestions for care or treatment--especially when they thought these suggestions were "reasonable" or "medically necessary." (In one extreme interpretation, a doctor defined lack of cooperation as "someone not willing to go by the basic tenets of the sick role." [KF, male, physician/administrator) Obstructive behaviors included "noncompliance", "refusing treatment", "not listening to or agreeing with providers' recommendations," and "lack of motivation to get well." Together, these behaviors were cited as difficult by 51 providers (25 doctors and 26 nurses; representing 81% of providers) a total of 121 times (representing 26% of providers' total citations of behavioral difficulty)

Providers often defined uncooperative patients as "refusers." They "don't do what we ask the to do," an intern stressed. For example, "

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example, "they won't stick to a diet or won't lose weight." [CN, male, intern] or they "refuse procedures and tests" [CM, female, attending;

Table 6:1 Conceptual Categories of Behavioral Difficulty

	Doctors N=31 providers citing yes responses	Nurses N=32 providers citing yes responses	Total Providers N=63 providers citing yes responses
Obstructive Behaviors:			
lack of cooperation	17	21	38
noncompliance	20	9	29
refusing treatment	10	13	23
refusal to listen	8	6	14
lack of motivation, commitment	6	6	12
refusal to agree	5	-	5
Manipulative Behaviors:			
drug seeking	16	15	31
manipulation	15	15	30
working the system	14	9	23
pain	9	9	18
seeking services	6	6	12
seeking secondary gain	6	-	6
sabotage	3	2	5
dr. shopping	8	-	8
Abusive Behaviors:			
verbal, physical abuse	21	21	42
combativeness/ hostility	5	15	20

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Table 6:1(con't) Conceptual Categories of Behavioral Difficulty	Doctors N=31 providers citing yes responses	Nurses N=32 providers citing yes responses	Total Providers N=63 providers citing yes responses
Challenging Behaviors:			
demanding time,service	20	15	35
coopting provider role	12	2	14
asking too many quest	1	-	1
Attention-Seeking Behaviors:			
complaining	17	6	23
wanting attention	10	4	14
helplessness	3	-	3
Crazy-making Behaviors:			
unreasonableness	16	6	22
somatization	6	-	6
Irresponsibility	13	6	19
Ingratitude	7	4	11
Total Citations	275	192	467

also RS, male, intern]. Nurses defined uncooperative patients similarly as people who "don't want any vitals done, don't want any medication" [CK, female, RN] or "don't want you to do certain things that need to be done," [AY, female, LVN], ultimately "blocking the treatment" [EH, female, RN] and making it "difficult for you to get your job done." [AY, female, LVN] Providers generally interpreted lack of cooperation as a "willful" or "intentional" act that indicated patient "resistance," "defiance"," or "antagonism." But lack of cooperation also encompassed more passive behaviors including a "lack of commitment to get better," "lack of motivation," and not "making an effort."

Although most uncooperative patients were considered refusers, the converse was not always so: not all refusing patients were thought of as uncooperative. Refusal of care represented a special case of lack of cooperation, and one that sheds light on the complexity with which providers think about all types of obstructive behavior. Almost to a person, providers staunchly affirmed the theoretical rights of patients to refuse treatment. "Patients," one intern assured me, "have the right to refuse anything they want. I never find that difficult." [KS, female, intern] And another intoned, "Everyone should be able to determine for themselves what they think is worth doing and what is not worth doing." [RS, male, intern]

But despite such invocations, the right of patients to refuse care or treatment was by no means clear or secure in actual practice. Rather, it was conditioned on a number of critical clinical and moral factors. Important clinical factors included the patient's age and prognosis, the provider's certainty about the efficacy of treatment, and the normative risks of treatment. If a patient was young, if the prognosis was good, if treatment had a "reasonably" good chance of working, and if the risks of treatment were small, patients had few rights of refusal. But if a patient was elderly, if the prognosis was poor, if the efficacy of treatment was unknown or conjectural, or if the risks of treatment were high, patients were generally given rights of refusal. As one respected resident said:

> There are [elderly, gravely ill or terminal] patients who have decided that they don't want to have any more hospitalizations or they don't want to have any more surgeries. That's quite common. That's a conscious decision. I don't find that difficult at all. It's fine, it's acceptable. [But when] they're uncooperative without reason, that's different...If a patient has positive stools, and you get a barium enema and find an absolutely treatable bowel cancer but they refuse the surgery, that's not acceptable...It's one thing to refuse treatment and to refuse care, but when something is extremely safe or there's no pain involved, no risk involved, and can potentially help them, I just can't understand sometimes why they refuse...and that really bothers me. [JJ, male, resident]

Providers' assessments of patients' rights to refuse treatment and care also depended on moral factors. Among these are (a) the degree of personal responsibility explicitly accepted by patients for refusing treatment, and (b) the willingness of refusing patients to voluntarily exit the practice of providers with whom they refuse to agree. If patients were "explicit" about not wanting treatment and accepted full responsibility for the consequences of their actions, or, alternatively, if they just "went away" and no longer sought treatment from a provider, their rights to refuse treatment were virtually guaranteed, even when clinical conditions for refusal were not met. "Not following a treatment I have prescribed is okay," the chief resident told me, "as long as we both understand that that is what they are going to do. But if they say I am going to this and they don't follow through with the medication or therapy, that's not okay." [CH, male, chief resident] An attending physician echoed similar sentiments: "Say a cancer patient refuses treatment saying, 'Well I'm going to die from this anyway. I don't want to have surgery.' As long as they understand the consequences of their decision, that's completely their right." [CM, female, attending; also JR, female, attending] And speaking to the conditional right of patients to refuse treatment as long as they left his practice, a resident who represented the thoughts of many said: "I think that often the gut response is, "if you don't want to take my advice, why are you here? Go somewhere else." [SB, male, resident; also CM, female, attending; KS, female, intern; BZ, male, attending]

The issue of responsibility raised by questions of patients' rights to refuse treatment is centrally important to providers' understandings of difficulty. Medical ethics and standards of care dictate that providers must assume responsibility for the care and treatment of patients who want help (especially those who are sick and want help). This is the crux of a predicament for providers: They are personally and professionally obligated to help patients who say they want help. But when such patients refuse treatment, and do not explicitly assume responsibility for doing so, providers find themselves in the untenable position of providing mandated care to (and being responsible for) patients who they don't like and will have poor outcomes. As one intern said: "Patients who are noncompliant but want to be helped by [me]--and yet [I] can't because they are not working with [me]--are the hardest patients for me to deal with." [WB, male, intern] Simply stated, providers did not want to assume responsibility for the care and management of patients who refuse to cooperate with them.

The issue of specifying responsibility also lies at the heart of providers' efforts to hear explicit statements from patients for assuming the responsibility of their treatment choices. One physician explained

> I have a box of DPA (durable power of attorney) forms and we talk about [their treatment preferences]. I document it in the chart and then if the patient goes in and refuses therapy, I can say we previously talked about this. They did not want surgical treatment or whatever; Then you can feel very comfortable with it. [JL, male, attending]

Some obstructive behaviors, especially refusing treatment, noncompliance, and not listening were sometimes associated with Russian patients. "Russian patients refuse persantine thallium tests...they won't listen to me or anybody else...The minute you say persantine, they so no." [CN, male, intern] A Russian neurologist affirmed that Russian patients often refused treatment or were noncompliant. She offered an explanation

> Some Russians, like high level executives or physicians, feel that they know everything. And they do [know everything]. So that can make it difficult. And another thing is...they're not used to listening. [They] want to know, they want to understand why this, why that. I think it's reasonable. They question why. They're told to use this drug, medications, and they don't do it. Somebody, a neighbor, will tell them it's not good for you. I took it three years ago and I get a problem. That could be more frequently seen in Russian patients than in American patients.

An example of a mundane obstructive patient: Mrs. H was a 53-year-old black woman who appeared in the ER complaining of abdominal pain and swelling, and difficulty breathing and walking. She had a history of hypertension, diabetes mellitus, coronary artery disease, hypothyroidism, chronic lung disease, and end-stage renal failure. The diagnosis in the ER was renal failure. In medical notes and during nursing rounds, she was described as difficult by her attending physician, a resident, a social worker, and utilization review nurse because of her obstructive behaviors, which consisted primarily of being overweight (she weighed 318 lbs.) smoking, and refusing to follow medical orders. During her subsequent hospitalization, she was described in medical notes as being "massively obese" and "unfortunately still smoking two packs a day." A resident wrote: "Although she claims diuretic compliance, I wonder about this." She was considered uncooperative because "she refuses Foley S and also is not saving her urine, so difficult to know objectively whether any diuresis has happened and thus extremely difficult to adjust diuretic drugs." This," the utilization reviewer reported, "is a difficult patient." [EM, female, RN] "She is extremely noncompliant in everything." [AG, female, social worker]

Manipulative behaviors

Putative examples of manipulative patient behavior are well documented in medical studies (see Grove 1978; Katz 1996; Short 1994) and, as previously detailed, constitute an essential category of difficult patient behavior in medical school texts on doctor-patient interaction (see Barker et al. 1995). In previous research (Fineman 1991a), I described providers' definitions of manipulative patient behavior in a clinic and social service agency for elderly adults. Staff members of that organization defined manipulation in terms of specific behaviors including "working the system," "doctor shopping," "seeking medical and social services inappropriately," and "sabotage".

Providers at this hospital confirmed that manipulative patient behaviors are a significant problem, and they defined manipulation in many of the same ways that have been previously described. Their definitions of manipulative behavior included "drug seeking," "working the system" ("improperly" manipulating the rules of the system to derive some kind of personal benefit; "people who are just not interested in their health and use the system repeatedly." [BZ, male, attending]), "complaining of pain," "seeking secondary gain," "sabotage," ("actively working against a proposed treatment plan or actively negating any attempts that [providers] propose" [BZ, male, attending]) ."doctor shopping" ("playing doctors or medical teams against each other" [KS, female, intern; also seven other doctors]), and "seeking inappropriate or undeserved medical or social services." Together, these behaviors were cited by 46 providers (25 doctors and 21 nurses; representing 73% of providers) a total of 133 times (representing 28% of providers' total citations of behavioral difficulty).

Providers considered manipulative behaviors to be devious, willful behaviors or actions by patients for the purpose of obtaining "secondary gain" [WB, male, intern], "some type of reward" [DC, male, resident], "special privileges" [EM, female, RN]," or "a good deal." [AH, male, attending] These benefits included a wide variety of perceived ill-gotten gains such as mood-altering and pain-killing drugs; assorted social services from taxi vouchers, to low-cost housing, to home aides; needless referrals to medical specialists; unnecessary hospital or emergency room admissions; exemption from arduous physical therapy; or just attention. The following examples illustrate two mundane cases of manipulation. In the first, an intern talks about the inappropriate use of emergency rooms by manipulative patients; in the second, an attending physician describes an encounter with a drug abuser who works the system by doctor shopping:

> *Example 1*: [T]hey abuse the emergency room system. They're not going through their primary M.D. They're not actually using any sort of preventative medicine...There is nothing worse than having a patient coming to the ER at four o'clock in the morning with a bump on the head that's been there for seven days. But they want their medical care when they want it and that's why they come to the emergency room and not necessarily when it is appropriate. [CN, male, intern]
>
> *Example 2*: The first patient I got in private practice was a woman who was late 30s, and she'd been on disability for 10 or 15 years for back pain and had seen literally 40, 50, 100--I don't know how many--different physicians and specialists. I think she had seen every single back specialist in the area. That's not an exaggeration. I mean she literally, in the time that I was taking care of her for a month, listed 10 different names of back specialists she had seen. She came for her first appointment 45 minutes late because she slept through it, and was basically doped up with drugs demanding this referral and that referral and so forth. I didn't give her what she was looking for and she quickly moved on to somebody else. [CM, female, attending]

In most cases of manipulative behavior, providers ascribed to patients "use of [an] ulterior motive or agenda that is not usually clear, so you have to pick them out. [DC, male, resident; also, WB, male, intern, CN, male, intern] They usually described manipulative

patients as trying to "trick" them, "rip [them] off," or "get them to do something which is not honest or in a patient's best interest." [WB, male intern;also HB, male, physician administrator; DC, male, resident; AH, male attending; EM, female RN; JP, female RN] Providers claimed that manipulative patients used a number of standard tactics to get what they wanted. Among these were use of "persistence," "pestering," or "demands" [MM, female, RN; JR, , male, intern; CM, female, attending; AH, male attending]; use of "threats" or "intimidation" [JP, female, RN; JR, male, intern]; "doctor shopping;" and negotiating a quid pro quo in which the patient agrees to do something the provider wants (for example, comply with a treatment regimen) in return for getting something the patient wants (for example, extra pain meds). "They won't allow you to help them except for things that will be exchanged for some kind of reward, usually some kind of substance--to be able to smoke or have some kind of privilege or some type of extra pain medications, opiates, and such," an intern explained," [WB, male, intern] Another intern illustrated a patient's use of the exchange:

> I had a patient with skin abscesses [who] wouldn't allow me to examine her unless I prescribed her certain pain medication for her problem. I needed to check her skin out and it left me in the precarious position of [doing] no treatment versus [doing a] half-correct treatment plus what she wanted. [CN, male, intern]

Providers' reactions to manipulative patients were diverse. Interns sometimes reported feeling "guilty" [KS, female, intern] or "like a heel" [DC, male, intern] for withholding pain medications from patients they suspected might be drug abusers but about whom they

were ultimately uncertain. But just as likely, doctors and nurses reported that they were sometimes "intimidated" [JR, male, intern; JP, female, RN] by drug abusers. Mostly though, providers said that manipulative patients made them feel "ripped off"--"like a schmuck" one said [KS, female, intern]--because such patients "act[ed] as though you're stupid, [that] you don't understand what they're trying to do. [JP, female, RN] In most cases manipulative patients left providers feeling angry, exasperated, and frustrated.

Providers associated manipulative behavior primarily with three groups of people: (a) drug abusers; (b) Russians; and (c) manipulative personality types. The manipulative behaviors of Russians have already been discussed at length and need not be mentioned here. Providers considered drug seekers to be the most common type of manipulative patient. "I guess," one nurse said, "that the thing that I think most of all [about] manipulative patients is [that they want] pain medication, or anti-anxiety medication, or some type of medication that alters how you feel." [MM, female, head nurse] The most common tactic for seeking drugs (although all were used, often in combination) was complaining about pain. "The most common problem that I see are patients running Tylenol with codeine tablets for whatever it might be--low back pain, severe headaches, any kind of pain--and it's especially obvious when the patient is a doctor shopper and trying to get these pills from hospitals all around the city. The last category of manipulative people were "manipulative types," described by an intern as "classic Axis II personality disorders." [KS, female, intern]

A mundane case of manipulative behavior: The following example of a manipulative patient reported by an RN, the assistant head nurse, and a resident illustrates a difficult case of manipulative behavior and makes clear the suspicion, anger, and frustration such patients breed. Manipulative patients leave providers feeling used and abused. "People get very personal, the resident said, "It's kind of like somebody calls you a name almost, and their reaction is personal. And it's like who do they think they're dealing with and why do they think they can do that to me?" The case describes how an alcoholic patient manipulated the system in order to live in the hospital for a few days to dry out, and in the words of one nurse, to get a "nice bed...food, and somebody to take care of her where it's warm and dry." [MM, female, head nurse]

Mrs. B. was a homeless and alcoholic middle-aged white woman. She was well-known to staff at Mt. Sinai and other area hospitals due to her frequent admissions. In the hospital she was perceived by providers to manipulate to get extra food and supplies. Mrs. B. had three hospitalizations during the previous two week at two different hospitals. The resident reported that the former hospital called and said she was a "nightmare patient." He said that he got "20 calls a day" about her. He reported that "she orders trays of food outside the instruction of the nurses...The first thing she does when she gets to the floor is call the nursing supervisor from her room, and order extra trays of food and says that she is being starved, that she is not being fed steadily...She was bitching for about 20 minutes [GC, male, resident]. A nurse reported that "she's a thief...She took the towels." [J, female, RN]

The following report by an assistant head nurse illustrates the anger and frustration that Mrs. B. provoked:

> Each time Mrs. B. keeps coming back into the hospital she's not acutely ill. In fact she looked better than the last time she left. And every time she leaves, she leaves with a pack of things, towels, cups, straws...(It takes you five years to do the belongings list, to put all that crap away that belongs to St. Luke's or St. Mary's because she makes the rounds.) And then she leaves here with twice as much stuff. It makes me sick! She's very manipulative. She always wants a private room. She gets real argumentative with the nurses about every little piece of her care. She really doesn't need to be here. She wants a wheelchair. Supposedly she's in here because of COPD--supposedly she can't breathe, she's got a respiratory problem. She was wheeling up and down the hallway--no oxygen on, good color, good respiration, good pulse. And she's just up and down complaining. People like that I don't have a lot of patience [for]... she was in here for probably about four days this last time. But she had just left a week and a half ago. And in the interim she was at St. Francis. She lives in hospitals She says that she has two children. I wonder. People like that really get my goat. I have a real hard time. If you don't have a place to live we can help you with that. But don't come in here and play lots of games. There are other sick people here. And you don't have enough time to do the things that you have to do. And when you have to deal with somebody like that, it's just frustrating all the way around. [CW, female, RN/ass't head nurse]

Abusive behaviors

Abusive behaviors comprise a group of threatening acts including verbally threatening acts such as "cursing," "yelling," "insults," "rudeness," "name-calling," and "profanity," and physically threatening acts such as "hitting," "biting," "spitting," "agitation," "hostility," "combativeness," and sexual advances. Although the number of providers' citations of abusive behavior represented a relatively small percentage of their total citations for all difficult behaviors (only about 13%), the domain of abusive behaviors nonetheless represented a difficult one for providers. Abusive patients were cited as difficult by 40 providers (21 doctors and 19 nurses; representing 63% of providers), and among those providers who cited abusive patients as being very difficult, some remarked that such patients were the most difficult for them to deal with. As one intern said, "The patients that I really [find] most difficult are the violent ones, people that [have] to be bed restrained, people who [are] trying to spit at you, telling you they [are] going to find you out later and even the score." [MS, male intern; also similar statements from AH, male, attending; DC, male, resident; CN, male, intern; MM, female, RN] Abusive patients were so difficult because they created personal as well as professional problems for providers. Commenting on the kinds of professional problems abusive patients created, a nurse said:

> Mr. A. is very combative and hostile. He doesn't like for you to do anything for him and he wants you to do it his way. It's hard to give him his medicine [because] he's fighting...He needs medication to calm down but if you're going to give him an injection, you can't give it to him. If you hold him down he's angry and if you don't give it to him he's going to be uncontrollable. [AY, female, LVN]

Even more than for the management problems they presented, abusive patients were difficult for the personal toll they exacted on providers. As one nurse said, "It's hard not to personalize being hit or being called names. It's hard to not get a personal emotional response." [MM, female, head nurse]

Based on their assessments of the purported cause of a patient's abusive behavior, providers perceived these patients in one of two distinct ways: They were perceived as either demented or as hostile, a perception that also marked the distinction between being perceived as either sick or bad. While the distinction often made little difference in the way in which such patients were handled (in both cases abusive patients were often likely to be chemically or physically restrained), it made a big difference in how such patients were thought of. Combative demented patients, though difficult, were sometimes regarded sympathetically. Combative hostile patients, in contrast were regarded as, in one resident's words: "plain old rotten--[people] who [are] antagonistic, abrasive personalit[ies], just malicious, and in general, the most difficult for me to handle. [DC, male, resident]

Two brief examples illustrate the differences between demented and hostile abusive patients.

Example 1, A case of a hostile abusive patient: Mr. P.: Mr. P. was an 85-year-old man of Polish ancestry who lived in a poor city neighborhood and spent his days collecting bottles. He was brought to the ER by his landlady after he fell and fractured his hip. During a previous admission for anemia he left the hospital AMA (against medical advice) after insisting on getting a walker. In medical records and in interviews he was described as among other things, "verbally abusive," "offensive," "belligerent," and "combative." "He's very unpleasant," an intern told me. [MZ, male, intern] A resident concurred,

> "A lot of times he would swear at the nurses and [me] in Yiddish or whatever language he was speaking. Nurses who spoke Yiddish and translated said to me: 'Do you know he just called you a whore?' I just tried not to acknowledge it." [MM, female, resident]

What made Mr. P a hostile combative patient was the intentionality of his actions. The resident confirms this by saying "He was belligerent and offensive, and he knew that he was. That's the whole difference in classification of difficult." [MM, female, resident]

Example 2. A case of a demented abusive patient: Mr. J: Mr. J. was described in medical records as "an unfortunate 36-year-old gentleman with end-stage AIDS complicated by CMV retinitis, dementia, and PCP. He was admitted to the hospital with increasing weakness and disorientation. A psychiatric evaluation summarized that he "exhibited deficits in...orientation, mental flexibility, memory, concentration, and judgment. Additionally, emotional factors impact upon his ability to contain anxiety and impulsive activities." In hospital he was often confused and expressed suicidal ideas. On a number of occasions he pulled out his passport needle and attempted to stick himself and staff members with it. Although he was considered dangerous by some staff members, his behavior was not considered intentional. "It's not purposeful," an intern remarked. "Although he's completely unpredictable, there is no malice. [His behavior] is secondary to dementia." [JB, female, intern].

Challenging Behaviors

Providers defined as challenging, three patient behaviors that they perceived impugned or tested their professional authority and competence. These patient behaviors included: (a) diagnosing, medicating, or treating oneself without medical advice; (b) demanding specific diagnostic tests, medications, or treatment plans; and (c) asking too many questions. Challenging behaviors were cited as difficult by 39 providers (24 doctors; 15 nurses; representing 62% percent of providers) a total of 50 times (which was equal to 11% of all providers' total citations of behavioral difficulty)..

Many providers (doctors in particular) viewed dimly patients who presented themselves with a fully hatched diagnosis and treatment plan (rather than just "giving their symptoms" [LK, female, attending] "for example," an intern pointed out, "people who come into the clinic with back pain and say, 'I have kidney pain,' or patients who come in and say, 'I have liver disease' because they have a bitter taste in their mouth between meals." [CN, male, intern]) or who demanded specific diagnostic procedures, medications, or treatments ("They come in and say, 'I want to go to ENT,' and I haven't decided whether [they] need to go to ENT or not." [LT, female, intern] or who instruct providers too closely on how to perform a task ("They want you to bathe them slowly or they want you to spend time talking to them." EH, female, LVN]. Many providers interpreted such behaviors as "hostile" acts [LK, female, attending; MM, female, head nurse], which they believed were intended to co-opt their professional status and directly challenge their expertise and authority. An attending physician illustrated with certainty the dim view she took of patients who she perceived were attempting to challenge her authority and expertise:

> It's totally inappropriate for patients to be--and I don't allow my patients to be--in control in that they walk into the room and say, 'I need a CAT scan, I need a chest X-ray, [I need] an MRI and...a referral to opthamology, gynecology, orthopedics, ENT, etc., etc. That's not something I allow them to control and they have no business controlling it." [CM, female, attending; similar sentiments also reported by LK, female, attending; LT, female, intern; CN, male, intern; JR, male intern]

Providers reported that such behaviors demonstrated that patients devalued their work, which they considered special or even unique. "It's frustrating," an intern lamented, "because I'm just the gatekeeper. They're not giving [me] credit. They just want to be sent on." [MS, male, intern]

Providers expressed similar sentiments about patients who asked too many questions about their care and treatment. They interpreted intensive patient questioning about their decisions or suggestions as "tests" of their competence, and as markers either that patients "feel that they know better than the doctor" [SB, male, resident], or more commonly that patients did not trust or value their expertise and considered them "just another physician." [LK, female, attending] Some nurses felt the same way. Speaking about a patient who questioned her every day whether or not she was being given the correct meds, an LVN bitterly said, "Ms. T. didn't want to take [meds] from me. She was the type of person that you had to explain everyday the same medication to her. She took you to the 3rd degree and that can be annoying sometimes...It's like putting you through a test. It's testing you." [AY, female, LVN]

Although many providers resisted challenging patient behaviors, some of them (and even some of those who resisted) recognized challenging behaviors to be a problem of degree, rather than one of kind. They acknowledged that challenging behaviors sometimes represented a positive patient quality of "showing interest" in their health care, "taking an active role," and being "motivated, or that such behaviors expressed patients' inherent right to advocate for themselves. "Not every patient who is demanding is a difficult patient," one intern cautioned. [CN, male, intern] And another added, "I think being demanding in some people is...great. Its shows that they have some life in them, that they're interested." [RS, male, intern] Problems emerged when patients' demands were inconsistent with providers' wishes.

Providers associated challenging behaviors with three groups of people: (a) AIDS patients, who one physician noted, "often feel that they know better than the doctor;" (b) Russians; and (c) patients who (because of some personality disorder) had unusually "fixed ideas" or "very set concepts" about their health care.

Attention-Seeking Behaviors

Providers defined attention-seeking behaviors broadly to include "complaining," especially about "trivial problems," "minor pains," "other doctors," "everything," or "problems that have no clearly defined etiology;" and also excessive helplessness or dependence. Attention-seeking behaviors were cited as difficult by 31 providers (22 doctors and 9 nurses; representing 49% of providers) a total of 40 times (presenting 9% of providers total citations for all difficult behaviors).

As with challenging behaviors, two central features of attention-seeking behaviors were that they were perceived as difficult only after a point, and only when they were perceived to be "exaggerated for the purpose of getting attention."[1] [SB, male, resident] In short, most providers tolerated some amount of complaining and helplessness in patients before identifying them as difficult. Indeed, some providers saw nothing wrong with patients' seeking attention, and stated that attention giving was in their job description. One intern, for example, said, "Most of my patients have problems. Even the ones that come in and cry...are fine. They need help. It's not medicine. They just need me to sit and listen. And I like doing that. That's part of the people part." [KS, female, intern] But this attitude was generally more prevalent among nurses, who often depicted nurturance as an important aspect of their work. Sometimes," a nurse said, "the patient can be on the light and just want attention. That is what I try to find out. And sometimes they say yes (laughs). They just want to talk to somebody, and that's OK." [J, female RN]

But for many, attention-seeking was not appropriate behavior and was perceived (especially by doctors) as a drain on their time and an impediment to performing their work. Most providers characterized attention-seeking behaviors negatively as "whining," "crying," "kvetching," or inordinate "moaning and groaning." Whining, in particular, annoyed them. "There's just something about the whining tone of voice that really sets [me] off about somebody," one intern said. "It makes all of their complaints seem terribly trivial." [MS, male, intern] And another concurred, "They launch into a series of complaints and don't let me get a word in edgewise. There is a high-pitched, almost screaming kind of voice. [JB, female, intern]

Providers associated attention-seeking behaviors with two kinds of people: Russian émigrés (of course); and people with narcissistic personalities, who they surmised were "lonely," "screwed-up," "pity- or love-seeking," or "without recognition" [EL, female, RN; CN, male, intern; JJ, male resident], and whom they described as "acting like children" and "behaving like kid[s], looking for limits" [JJ, male, resident; JB, female, intern; CN, male intern] Speaking about patients who constantly complained of minor pains, one physician said,

> You know, there's a certain kind of personality...They're going to be very dependent, very whiny, the pain becomes an integral part of their personality, in fact the major focus of their life. A lot of these people if you took their pain away, they'd have nothing left. That's what they talk about, that's their life. [KF, male, physician/administrator]

"Crazy-Making" Behaviors

The practice of Western medicine is predicated on, among other things, principles of reason, logic, and rationality. Providers presume that they and their patients (with the exception of psychiatric and Alzheimer's patients) are guided by and operate under these same principles. Violations of these principles incur difficulty. "When you don't have [logic and rationality]," a physician warned, "it becomes crazy-making." [BZ, male, attending]

Providers defined crazy-making patient behaviors in two ways: (a) as behaviors that "ma[d]e no rational sense" to them, that were, literally, crazy [JJ, male, resident], and (b) as behaviors that drove them (figuratively) crazy. Such behaviors indicated to providers that patients were "out of control." [JJ, male, resident]. But even more important, they indicated to providers that their work was out of control. Crazy-making patients turned the orderly and predictable routines of providers' world topsy-turvy. Crazy-making patients acted in irrational, incomprehensible ways that violated and undermined providers' sense of logic and rationality, and, in the words of a resident, made it difficult for them to "maintain control...in order to make the hospital and medical care services run smoothly,...make [their] job work, and make [their] responsibilities upheld." [GC, male, resident] "When I think I'm being made crazy by a patient, an attending physician, remarked, "I lose it."

Providers cited as crazy-making behaviors being unreasonable, having unreasonable expectations, and somatization. Crazy-making behaviors were cited by 23 providers (17 doctors and 6 nurses; 37% of providers) a total of 28 times (representing 6% of all providers citations of difficult behaviors.).

In the absence of demonstrated psychiatric or cognitive problems, providers expected patients to be rational, reasonable, and sane. To the extent that they were not, some providers perceived them to be difficult. Providers viewed patients as unreasonable when they either (a) acted in unreasonable ways, or (b) "[could] not be reasoned with." [JJ, male, resident] Acting in unreasonable ways included being unreasonable or having unreasonable expectations of providers. Providers found such patients to be extremely frustrating. The following story, related by a resident, describes how an unreasonable patient violated his sense of rationality and frustrated him:

> I saw a patient, a young black guy, who came in with a pneumonia and pericarditis. He was having chest pain and we wanted to make sure there was nothing wrong with his heart and lungs. He seemed like a reasonable, rational person. (Usually you can identify some psychiatric problem when someone isn't making any sense.) He had a little bit of abnormal lungs. He denied drug use, he was in school and I believe he didn't use drugs recreationally. We wanted to place a P.P.D. [purified protein derivative, substance used in intradermal test for tuberculosis] on him to make sure he didn't have tuberculosis or hadn't been exposed to tuberculosis, and he refused it. He didn't like needles or the blood draws. I sat down with him (his mother was there too) and said: 'It's a very small needle, the pain is minimal and it's very safe.' He was worried about all the tests that we did. I explained [that] it's very safe but [that] if you have tuberculosis it's very serious and you can die from it. I said to him, 'This is such a simple safe test, the pain is minimal, let's just do it.' I told him I do it on myself, once a year while I'm here, and [that] if he were my brother, I would highly recommend this test, it's so simple. He just refused it, over and over. I don't understand; he's a smart kid, his mom was there and the two of them just refused it. I couldn't make any sense to it. There's not a risk of them and it's really not a painful thing, a little bit of pain. But it just makes no sense. That's really frustrating. [JJ, male, resident]

Patients who were perceived as having unreasonable expectations of providers were also defined as unreasonable.[2] Many doctors claimed that patients all too frequently expected them to "cure all their woes, and all their pains, and all their social problems." [HB, male, geriatrician] "I think," a physician said, "that a lot of people expect that we're able to cure anything that walks by with a single dose of medication. So I guess unrealistic expectations is the broad category for that...people want a pill that will cure them of all evils within 30 seconds of swallowing the pill...They expect miracles. [CM, female, attending] Such expectations, providers complained, set them up for unfair criticism by patients. "They think the doctor has done something wrong," a resident said, "It just doesn't work that way. They don't realize in medicine we don't do a whole hell of a lot as far as the radical cures and saving lives." [JJ, male, resident]

A number of doctors reported also that somatization (which is defined in Thomas 1985 as: "The process of expressing a mental condition as a disturbed body function.") drove them crazy. "Somatization," as one attending physician explained, "is where patients have a variety of physical complaints that are always shifting and evanescent and difficult for them to pin down--certainly difficult for me to pin down. And once one of those complaints gets addressed to anybody's satisfaction it's quite predictable that they report similarly vague and difficult to handle complaints with another organ system."[3] [JL, male, attending physician]

The practical problems raised by somatizing patients were explained by an intern:

> When a person somatizes, you have to rule out their physical complaints, rule out serious pathology. You're stuck with having to determine how many things to rule out, and it usually gets to be a greater and greater expense in both time and money. And it's difficult before you can say, 'This is somatization.' Diagnosis and treatment require, months, if not years, and in medicine the sooner we can diagnose and treat something the better. [RS, male, intern]

Providers identified Russians and Mexicans (especially Mexican women, who one intern described as the "biggest somatizers" [RS, male, intern]) as crazy-making patients.

Irresponsibility

Providers defined irresponsibility broadly as a "failure," "lack of interest," or "unwillingness" of patients "to take of care [themselves]" or "do things in their own best interest." [HB, male, physician/hospital administrator; also JJ, male, resident; SB, male resident; RS, male intern] and similarly as an "unwillingness to help themselves" or a "lack of care about their own body," [HB, male physician; CM, female, attending; JJ, male, resident; CN, male, intern; EM, female, RN] Irresponsible behaviors were cited by 19 providers (13 doctors and 6 nurses) as being difficult a total of 19 times (representing 4% of providers total citations of difficult behavior)

Although patient irresponsibility oftentimes involved noncompliance, it was a more comprehensive concept than noncompliance--one that providers applied broadly to many lapses of patient behavior (not just those involving nonadherence to medical regimens). In particular, providers applied the term irresponsible to lapses in patient behaviors that they sometimes called "lifestyle choices." These included behaviors like smoking, ignoring dietary plans, and abusing drugs and alcohol, especially when these behaviors were perceived to have a negative impact on health, for example, "patients who have tracks and abscesses from skin-popping drugs [who] don't take their antibiotics when they leave [the hospital]" [MM, female, head nurse; EM, female, RN]; "diabetes patients who won't lose weight," [CW, female, ass't head nurse]; "people with lung problems that continue to smoke,"[JJ, male, resident; KS, female, intern; EM, female, RN]; "patients with bad knees who are obese" [SB, male resident]; or "drug and alcohol abusers who leave the hospital and don't even bother to fill their prescriptions." [EM, female, RN] The following statement by a nurse, illustrates a garden-variety case of irresponsible behavior:

> We just had a man in here with diabetes. He's going to be back soon...within the next couple of weeks with the sugar off the wall and everything else. We tried to hook in home care and we tried to do our little bit of teaching before he went home. But he had friends bring him food, he wasn't interested in losing any weight. [CW, female, RN/ass't head nurse]

Providers understandings of irresponsibility were different than their understandings of noncompliance in one other another important sense as well. To them, irresponsibility implied more than a mere lapse of appropriate behavior. Underlying irresponsible patient behaviors, they intuited a particular "state of mind" of patients, which they depicted as at once, "self-destructive," "depressed," "apathetic," and "intentional." Irresponsible patient, in sum, were people who "[could] change their behaviors, they just [didn't] want to" [KS, female, intern]

As with the difficulty of patients who refused treatment (itself a potentially irresponsible behavior) the difficulty of irresponsible patients was predicated not only on the behavior per se, but on two situational conditions of the behavior: (1) that the patients would not "go away"; and (2) that they wouldn't take responsibility for being irresponsible. Providers often described irresponsible patients as difficult because they "always resurface, come back, and show up again" [SB, male resident]; "come back regularly, constantly [CM, female, attending] "come in again and again" [CW, female, RN]; "come in repeatedly" [BZ, male attending; CM, female attending]; are "booked right back in here [the hospital] wanting their symptoms addressed."[MM, female, head nurse] As previously discussed, the first condition requires that the provider take responsibility for the patient, and the second guarantees that the patient will not comply with the providers' wishes.

Providers associated irresponsibility with three groups of people: alcohol and drug abusers, Russians, and sometimes young people "because they don't think anything's ever going to happen to them [CW, female, RN]

Two Cases of Behavioral Difficulty

Case Study 1: Mr. M., a case of mundane behavioral difficulty. The case of Mr. M. is a typical case and illustrates how and why patients are perceived to be difficult when they challenge providers. It also serves as an excellent illustration of how ordinary and everyday events and miscommunications render patients difficult in providers' eyes..

Mr. M. was a 67 year-old white man who presented in the ER with hypertension, septic shock resulting from a recently performed (and botched) needle biopsy of his prostate, and a mild MI. During his subsequent hospitalization, he was identified by a resident and an intern as difficult because of his challenging behaviors, which included asking too many questions, "consuming a lot of people's time in taking care of him," and "constantly questioning everything we did." Anyway," the intern said, "I think he got under my skin." [RS, male, intern] This intern judged that Mr. M.'s inappropriate behavior was the result of his being "high-strung" and "kind of an uptight personality."

During the previous two days, two specific incidents triggered Mr. M.'s questioning of the house staff. The first involved a change of medication about which Mr. M. was not informed. (The previous evening Mr. M.'s physician ordered that he receive a new regimen of oral antibiotics to replace the intravenous one that he had been taking previously. The physician stressed to Mr. M. the importance of this change. The following morning he was given something entirely different). The second incident involved his being given an incorrect dosage of his regular beta-blocker as a result of the hospital pharmacy misreading the order.

Mr. M.'s intern acknowledged that, in general, patients' questioning is a "two-sided issue" (because such behavior "shows me that they're interested in taking care of themselves usually and that they're taking an active role in their health care" and because patients "do well when they are very interested in their own health care"). Nonetheless, he maintained that Mr. M.'s questions and issues were picayune and purposefully provocative. In other words, Mr. M. was looking to make trouble. He stated that Mr. M. did not need to "be so concerned about some of these little details. In the big picture," he said, "they were pretty small points."

Mr. M.'s own description of the events and interactions in question fill in the critical details of the story (details which were largely unknown to and unsolicited by the house physicians) and paints a very different picture of them. In contrast to the ways Mr. M.'s physicians represented him, Mr. M. thought of himself as a "knowledgeable" and "decisive" patient, and had a different take on the situation. In conversation he said to me,

> You heard the tizzy I was in. You should be aware of what happened. Yesterday my physician sat down and said that he was taking me off the antibiotic that I had been taking intravenously. He wanted to put me on four antibiotics for 24 hours to see if that would maintain my temperature before I went home. He said: ' Don't forget, tomorrow morning when the nurse comes in to get it.' And I heard last night I was getting it. But this morning the resident said I should have one more dose [of the intravenous antibiotic] and he also changed the antibiotics that the doctor ordered.

> When my doctor comes in this morning he says to me, 'What are you making such a fuss about? I said, 'What do you mean what am I making such a fuss about? You sat here for twenty minutes telling me why you were not going to give me the antibiotics intravenously." Then I looked at him and I said, 'You know, you really have a nerve because when I had gout and stopped using the drug you prescribed you said to me, 'If I order a medicine and tell you to take it, I mean you should take it. So [this morning] all I kept hearing you saying was, 'I sat here and told you not to take the intravenous drug. Why did you take it?'
>
> The reason [that I didn't get the oral antibiotics] was that they didn't have them in the hospital, they had to order it and you can't go a whole day without antibiotic. I said 'Well why didn't somebody come in and say 'Hey, we can't get the antibiotic that we want to give you. We feel that the antibiotic that the microbiologist ordered is a better antibiotic than the one your doctor ordered if your particular infection will not respond to this one.' I would have understood the whole thing. Instead I worked myself up into a real fit, which I shouldn't have but I did...There were so many people that have been in here poking at me and carrying on and asking questions, one of them could have come and said, ' Oh, we're going to have to do this because we can't get the oral antibiotic. I could have understood. I'm not an idiot.

Case 2. Ms. S., a case of extreme behavioral difficulty. Mrs. S. was a 72-year-old unmarried white professional woman. When I first met her on the rehab unit, she appeared extremely frail, thin-skinned and exhausted. She looked many years older than her 72 years. He hair was white. Her face was thin, wan, lined and drawn. (Interestingly, she was described in a note by one of her physicians as "middle-aged".) She was unable to speak because of ventilator and trachea hook-ups. A well-written sign above her bed read: "PLEASE. Ask me only question that require a yes or no answer." She also kept a yellow legal pad next to her bed. Despite her disabilities, Ms. S.

was fiercely independent. She told her cardiologist that she had "a strong will to survive and to improve."

Ms. S had a ten-year history of recurrent asthmatic bronchitis and arteriosclerotic heart disease marked by ventricular tachychardia. Approximately three years ago, Ms. S., despite her strongly expressed preference for an alternative drug regimen, began drug therapy with Amiodarone, an antiarrhythmic drug. Because of its high level of toxicity, the PDR recommends that Amioderone be used only for patients with life-threatening arrhythmia. Amiodarone therapy results in rates of potentially fatal pulmonary and respiratory toxicity as high as 10% to 15%. It is not recommended for patients with ventricular arrhythmia or a history of pulmonary disease.

Six months after treatment with Amioderone began, Ms. S. was diagnosed as being in congestive heart failure as a result of Amiodarone pulmonary toxicity. The diagnosis was confirmed by pulmonary biopsy. Treatment with the drug continued, however, for another four months. At that time, Ms. S. developed chronic respiratory failure which was also secondary to the Amioderone. As a consequence, she required a tracheostomy and prolonged mechanical ventilation.

Over the next two years Ms. S. was hospitalized nine times (a medical history that is documented in 14 volumes of medical records). These hospitalizations were primarily for acute bouts of pneumonia and congestive heart failure but also included a seven-month admission to the rehab unit in order to wean her off the ventilator, a course of treatment that was apparently successful.

Upon her departure from the unit, however, she had an argument with the head of the unit and reportedly told him: "You haven't done a damn thing for me."

It was during this admission that Ms. S. became identified as a difficult patient. Ms. S. was assessed as difficult because of her difficult personality and was perceived as being unwilling to conform to her doctors' and nurses' expectations. Medical staff on the rehab unit referred to Mrs. S. as "demanding", "uncooperative", "manipulative" and "willful". "Everything had to be done her way," a doctor told me. "No compromises."

Ms. S. had a reputation for "refusing treatments" and for "firing therapists and refusing to work with them." When asked what made her so difficult, one therapist told me: "It centers on the issue of control. She wants to be in control even if it is medically not in her best interest."

"She pits staff members against each other," a nurse told me...She picks and chooses who she wants to take care of her." Another said "Everybody knows she's a staff-splitter...She's got everyone working but not together...She does her own ordering...She gets doctors to do what she wants."

Staff members used a number of strategies of confrontation and avoidance to deal with Ms. S. In particular, she was often rebuked by staff members. Here's one example: During a physical therapy session, the therapist wanted her to extend each leg to the side ten times. He asked her to do three sets of this exercise. On the third set, Ms. S. went completely limp and slumped over. The therapist had to hold her up. She started to slide off the bed requiring a respiratory therapist, who was also in the room, to help support her and push her back onto the bed. The physical therapist confronted Mrs. S: "C'mon Mrs. S. You don't have to be like that. Your legs just don't give out like that...C'mon Margie, I just don't buy it." Ms. S. just sat there limp and listless. They helped her to sit up in bed. She wrote a note saying: I know you don't think I'm trying but I am." The therapist said O.K. They would try again later.

In addition, staff members discredited the extent and severity of Ms. S's illness. A nurse, for example, told me that Ms. S. was unwilling to have an IV removed (an IV which this nurse thought was medically unnecessary) only because it "made her look sicker than she really was." This nurse commented that the ventilator was unnecessary too and that the tracheostomy hole probably could have been covered over long ago. Ms. S. did all these things, she thought, because she was "manipulating to keep herself on the unit." Most of the other nurses on the unit concurred. One said: "She doesn't need the ventilator. She's only on it since this hospitalization. She wasn't on it at home...The last time she was here, "she waited until the last two weeks to wean herself. She could have done it a lot sooner...But she did it "because she wants to assume the sick role."

The consequences of being perceived as intentionally difficult were devastating for Ms. S. Her interactions with medical, nursing and therapy staffs were generally unpleasant and problematic. In addition, her physicians and members of the nursing staff made it painfully clear to her that unless she weaned herself off the ventilator quickly, she was going to be moved to a nursing home. She was told again and again that she was not going be to allowed to remain on the rehab unit for many months as had been allowed on her previous admission. Rather than consent to institutionalization, two days before her planned discharge, Ms. S. summoned her lawyer and a nephew and had the ventilator withdrawn. She died about eight hours later.

Summary and Conclusions

In sum, behaviorally difficult patients were the most important source of difficulty reported by providers. Such patients accounted for almost two-thirds of all the difficulties that doctors and nurses reported. Providers described 28 different kinds of behavioral difficulty, which I have organized into 8 conceptual domains. These included: obstructive behaviors, manipulative behaviors, abusive behaviors, challenging behaviors, attention-seeking behaviors, crazy-making behaviors, irresponsibility, and ingratitude. Similar to their descriptions of other types of difficult patients, the providers at Mt. Sinai associated behavioral difficulty with Russians, drug and alcohol abusers, and sometimes AIDS patients. In addition, they often associated behavioral difficulty with people who they perceived were difficult or disordered/pathological personality types. Interestingly, virtually no one associated difficult behaviors with elderly patients. This is an apparent oddity given that old age was the most common of providers demographic correlates for medical and circumstantial difficulties. Moreover, many of the cases and examples of behaviorally difficult patients reported in this chapter were in fact chronologically old. What then accounts for providers perception that elderly people are not as a group behavior problems? I think perhaps the answer lies in the ways in which providers' subjectively constructed their understandings of old age, ways that precluded behaviorally difficult patients from being viewed as old. I have reported earlier (see Fineman 1994 in appendix IV) that one of the necessary criteria upon which providers' attributions of old age rested, was their perception of "old behaviors" such as social disengagement and lack of activity. Old people, from this perspective were mentally and physically inactive. These were qualities totally opposite to the ways in which providers conceptualized behaviorally difficult patients. Providers viewed behaviorally difficult patients as anything but disengaged and inactive; Indeed, they viewed them as being malicious, actively confrontational, powerfully hostile, and threatening. Behaviorally difficult patients were perceived as directly challenging their authority. And they did so intentionally. As a rule providers perceived that difficult behaviors were calculated and deliberate. As a consequence, they viewed behaviorally difficult patients with suspicion, hostility, and dread. Such patients angered and frustrated doctors and nurses and sometimes made them crazy.

Endnotes

1 In one case, an attending physician attributed a patient's constant complaining not to attention-seeking, but to a nasty disposition. He related to me the following story of this extreme case:

> I was covering for [another physician. A patient of his] came to the emergency room and he asked me if I would take care of the situation. It was my 40th birthday. I didn't really want to see this patient [but] I came in anyway since it seemed to be the right thing to do. All she did was complain the whole time about

> the service. I explained to her that this was my 40th birthday, that I was taking time out for this, that I didn't have to do this, and that she ought to just behave herself, which she did for about five minutes and went right back to complaining. Later on, she wanted to become my patient. One of the office people warned against that, say she's trouble. I said, 'She's a nice lady, she's confused, it's nonsense.' It turns out that she was a lot of trouble because all she did was complain about the other doctors who had seen her and how bad they were and how they should be taken out and shot or something. I realized I was a fool. I should have realized that most of these people are competent...and that I should have known better [than] to take her as a patient since people like that will eventually turn on you too. Of course, she did later on. We made a minor billing error which we corrected, which wouldn't affect her anyway, we billed Medicare twice for the same procedure. She decided that we were a bunch of fraudulent charlatans and so on and suggested that we were doing this whole thing to cheat her. [AH, male, attending]

2 An alternative view, representing the sole negative case, was expressed by resident:

> We always talk about patients' unreasonable expectations of physicians. I think there's a lot of unreasonable expectations of patients. I'm critical of my profession. I think we have a lot of unreasonable expectations of patients, like [for example], they should understand what we understand. It took us four years to go through medical school. It take a little longer than thirty minutes to understand why hypertension leads to potential death.

3 Somatization is different from the medical difficulty "uncertain diagnosis" in that it implies no organic pathology is present. As a consequence, diagnosis of symptoms in suspected cases is seen by providers as futile and a waste of time.

SECTION III

THE SOCIAL CONSTRUCTEDNESS OF DIFFICULT PATIENTS

As discussed previously in the literature review, difficult patients are often represented in medical and nursing research as a conspicuous, objective, and naturally occurring category of problem patients. Most of the providers in this study implicitly subscribed to this view. They accepted that difficult patients were self-evident--indeed, that they were intuitively knowable--by virtue of their problems and behaviors. As a consequence, providers presumed that they could identify difficult patients accurately and easily, and in addition, that their understandings about difficult patients were widely shared by their peers. In short, because providers believed that their judgments about difficult patients were based on observable, objective fact--not merely on subjective opinion--they believed as well that their judgments were valid and reliable. As one attending physician noted:

> [Knowing a difficult patient] comes from a feeling of patients that every doctor ought to have in practice. I think we all know what we mean by difficult patients. [There's] an intuitive sense--usually the initial impression is correct. I've identified a number of these. I have had people in my office identify them. They usually can tell even before [someone] makes an appointment if they're going to be difficult. [AH, male, attending]

Providers' beliefs that difficult patients were naturally occurring and self-evident, defined by shared understandings, and recognized in concord with one another were reinforced in everyday interaction with each other during rounds, clinical conferences, and in informal conversations. Providers implicitly confirmed each others' existing beliefs about difficult patients generally and about the identification of difficult patients in particular because they rarely discredited or disagreed with one another's judgments about difficult patients. Certainly nurses did not disagree publicly or explicitly with the judgments of doctors[1]; only rarely did doctors disagree publicly with one another's judgments; and only occasionally did nurses do so. Disagreements, of course, did sometimes occur (for example in nursing rounds). But when they did--when a difference in perception occurred between two nurses about whether a particular patient was or was not difficult--each typically refrained from explicitly discrediting the other's judgment. Instead, disagreements about a patient's status as difficult were framed in conditional and situational terms. For example, when a social worker declared in nursing rounds that a new patient on the floor was difficult, a nurse who cared for her the previous night disagreed by saying: "Well, I took care of her last night and she wasn't really difficult *with me.*" [AY, female, LVN; emphasis added] This statement only conditionally contradicted the social worker's remark and did not directly challenge either the accuracy of the statement or the judgment of the social worker. It did, however, leave the impression among those present that this was a patient that should be carefully scrutinized. In this way, providers' efforts to build collegiality and maintain civility in the workplace may have unwittingly contributed to perceiving patients as difficult by fostering a false sense of consensus among them.

Despite providers' confidence that they shared understandings about difficult patients, in fact, they often did not. Based on an analysis of their citations of the factors and domains of difficulty, the following chapter shows that providers sometimes understood difficult patients very differently from one another. Indeed, their understandings of difficult patients were marked by regular, systematic, and critical differences in the number, kind, and meaning of the factors of difficulty that they reported. These differences, moreover, were associated with differences in provider status and level of training. In particular, important differences distinguished the reports of doctors from those of nurses, and those of LVNs (in-training nurses) from those of RNs and nurse administrators (out-of-training nurses).

Chapter 8 identifies and investigates four specific differences in the ways in which doctors and nurses, residents and attendings, and LVNs and RNs/nursing administrators understand patient difficulty. Chapters 9 and 10 elaborate on and explain in depth two of these differences. I suggest that providers' understandings of difficulty and the differences between them may be explained by specific factors of their practices. These factors include, among others, their expectations of appropriate patient behavior, and their self-perceptions of their professional roles and responsibilities. Specifically, I argue that providers may describe as difficult those patients whose behaviors deviate from their expectations of appropriate patient behavior, who interfere with the successful performance of their roles, and who impede fulfillment of their responsibilities. Chapter 9 examines how differences in doctors' and nurses' understandings of behavioral difficulty relate to differences in their behavioral expectations of patients. Chapter 10 examines how differences between LVNs' and RNs' understandings of difficulty relate to differences in their self-perceived roles.

In sum, the three chapters document that difficult patients are, by providers' own descriptions, neither self-evident nor naturally occurring. To the contrary, difficult patients are socially constructed by providers in different ways based on their status, their training, and specific factors of their practices.

Endnotes

[1] Nurses sometimes acknowledged to me, however, that they disagreed with a doctor's assessment that a patient was difficult. For example, one nurse told me:

> A lot of patients get mislabeled and that really upsets me. They'll be mislabeled as being difficult. A lot of times I'll walk through and say [to myself] "This patient's not difficult if you really listen to him. I understand why they don't like this doctor. This doctor is not talking to him, or [is] talking above him." A lot of doctors talk over [patients'] heads.
