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Author

Trostle, James Alan

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MANAGING EPILEPSY:

A COMMUNITY STUDY OF CHRONIC ILLNESS IN ROCHESTER, MINNESOTA

by

James Alan Trostle

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Dedicated to the Rochester residents with epilepsy
who participated in this study,
especially those who were not sure what they would get out of it,
but were willing to give it a try anyway.

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MANAGING EPILEPSY:
A COMMUNITY STUDY OF CHRONIC ILLNESS
IN ROCHESTER, MINNESOTA

JAMES ALAN TROSTLE, M.P.H.

ABSTRACT

Epilepsy is a neurological disorder with a long history of social stigma and misunderstanding. People who have epilepsy, their families, and their physicians face diagnostic, therapeutic, and prognostic uncertainties. People who have epilepsy often must manage side effects from medications, unpredictable seizures, and discrimination.

Studies of the social and psychological repercussions of epilepsy commonly have drawn their samples from populations likely to make the disorder appear most disabling: hospitals, outpatient clinics, and social service agencies. This study approximated a community-based sample by using a unique diagnostic index based on medical records from the Mayo Clinic and all other health services surrounding Rochester, Minnesota. As of January 1, 1980, 199 non-retarded Rochester residents aged 13 to 54 qualified as active prevalence cases of epilepsy. All their medical records were reviewed in 1985-86, and personal interviews were conducted among 127 (79%) of the 161 adults aged 18 to 59 still residing in the area.

People with epilepsy manage their own medications. Notes in the medical record showed that 28% of 199 cases had discontinued medications on their own since 1975, and 14% had changed their own dosage for more than two weeks. At interview, 43% of respondents said they had discontinued their medications for three or more days, and 33% had changed their dose for more than two weeks. Comparing their records with self-reports,

almost 70% had changed or "self-regulated" their dosages in the past, and 33% had done so in the week preceding the interview. Discontinuing medications versus taking them at increased or reduced levels appeared to be distinct dimensions of self-regulation; dimensions lost when lumped under the epithet "noncompliant."

Compared to people from service-based samples, people from this community-based sample appeared less concerned overall about the effects of epilepsy on their lives, but they had similar types of concerns: employment and educational opportunities, and emotional problems. They worried about disclosing their condition, and especially their eligibility for driving. These difficulties are part of the "natural history" of managing this chronic illness, and can best be seen outside the doctor's office.

Frederick L Dunn

. . . . Frederick L. Dunn, M.D., Ph.D. (Chair)

23 March 1987

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Epilepsy is an illness that has long been the subject of discrimination, conjecture, and wonder. Few of us who twitch and jerk as we fall asleep link our body's movements to seizures, yet when these same benign movements occur repeatedly or in tandem with seizures they can be classified as one manifestation of epilepsy. Epilepsy--like cerebral palsy, leprosy, and some other chronic illnesses--excites a social horror far in excess of its frequency or hazard.

Epilepsy can be studied from clinical, social, and epidemiologic perspectives. These perspectives are distinct but complementary: clinicians are most directly concerned with diagnosing and treating illness; social scientists with understanding human behavior, beliefs, and attitudes; epidemiologists with studying how diseases are distributed and caused. Epidemiologists and social scientists do not lay hands on their subjects, and have no particular legal responsibility toward them. (They do have ethical responsibilities, but these are distinct from the codified and closely regulated responsibilities that physicians have toward their patients.) Clinicians draw from epidemiology and social science, and must translate concerns about etiology, risk, and stigma into individual recommendations and treatment plans. From the clinician's perspective, epidemiologists and social scientists have the luxury (and disability) of being able to step back from the necessarily individualized details of particular cases. Non-clinicians can better describe a comprehensive picture of illness risk and illness-related behavior, but are necessarily distant from the core of medical practice.

Among all the social sciences, anthropology can be seen as the discipline that prides itself on its ability to ascertain and explain beliefs. It can easily be seen as the polar opposite of an eminently quantitative discipline like epidemiology, which prides itself on its ability to explain the distributions and determinants of illness (Dunn and Janes 1986, Rubenstein 1984, Trostle 1986b). There is some tension within anthropology between those who look for cross-cultural uniformities, e.g., incest taboos, and those who look for cultural diversity or relativity, describing particular cultures as fully as possible. Some anthropologists even seem to specialize in finding that particular culture which will refute a postulated cross-cultural uniformity--this has been a source of frustration for epidemiologists and psychologists interested in building just such global models. But despite epidemiology's apparent strengths in its capacity to generalize findings, it still is unable to convey the meaning and human significance of illness--it is too often bound up in frequencies, risk factors, and probabilities to be able to describe the human side of illness and suffering.

These disciplines have contributions to make to one another, in addition to their respective contributions to clinical medicine. They could be thought of as distributed along a line, with anthropology and epidemiology at either end and clinical practice in the middle. I would prefer to envision them as points on a triangle. Anthropology can be a fertile source for questions, for describing the variety of human behavior, for understanding how broad generalizations must be if they are to encompass the true range of human adaptive variability. Epidemiology can be a fertile source for measurements of health-related outcomes--it is a language of techniques that can be taught, duplicated, and compared by different investigators. Some of these techniques can be used to answer anthropological questions, such as the frequency of particular health-related behaviors, the cumulative power of social and cultural variables to influence health, the separate contributions of sociocultural, clinical, and demographic variables to health outcomes.

I will adopt the role of interpreter in this study, travelling between the cultural idioms of physicians and their patients, at times using epidemiologic methods and data to assess these idioms most clearly. Anthropologists sometimes play this role to express one language or cultural idiom in terms of another, and thereby to make it intelligible, familiar, or at least recognizably different. Anthropologists have often interpreted, for general and scholarly audiences, the illness-related beliefs of the afflicted (e.g., Kleinman et al. 1978) and they are also beginning to explore physicians' belief systems (Hahn and Gaines 1985). However, they frequently concentrate on the beliefs of one to the exclusion of the other, or analyze exchanges between physicians and patients as though two systems of "explanatory models" were interacting independently of individual motivation and differentials in power and access to technological resources. Both belief- and power-centered explanations for behavior must be considered. Chapter Three reviews the clinical concept of compliance by including both types of explanations.

The history of epilepsy shows that disciplinary perspectives shape visions of illness. For most of recorded history epilepsy belonged more fully to healers of the spirit than to healers of the body. Only as scientists developed theories about brain functioning, treatments that altered seizure frequency, and an accompanying technology of diagnosis and assessment, did cosmopolitan biomedical healers who commanded this technology begin to have more control than those healers who commanded spirits. But this has meant that biological concerns have gained primacy in the study of epilepsy--understanding of the disorder is measured in terms of proximity to a cure and refinement of knowledge about nerve excitation, brain physiology, etiology, prognosis, and treatment. In the past century biomedical practitioners have used a limited pharmacopeia to control seizures, and most of their practice has consisted of diagnosing seizure type, choosing an appropriate anticonvulsant, and trying to achieve maximum seizure control with a minimum of side effects.

With the emphasis on biological aspects of epilepsy has come a diminution of concern for the social side of the disorder. The social world intrudes upon the biological world when physicians evaluate the potential harm done by a diagnosis of epilepsy, or when their diagnosed patients confront particular insurance or employment problems, driving restrictions, and other unique events. Physicians, and especially neurologists, are trained to reduce the social impact of epilepsy by reducing the number, frequency, and severity of the seizures. They are not--except for psychiatrists--usually trained to do formal social or emotional therapy, and are expected to refer cases needing such help to social workers, psychologists, and other professionals. In fact most physicians do a great deal of informal social and emotional therapy with their patients, as such therapy is unavoidable given the social context of illness. Nonetheless, from the perspective of the patient most social therapy is done by family members, friends, and other non-professionals.

Tests to measure levels of anticonvulsant medications in the bloodstream have confronted physicians more directly and frequently with their patients' behavior. Patient behavior is a crucial component of treatment plans: no matter how carefully physicians calculate doses and medication levels, many of their patients simply do not take the medication as it has been prescribed. Though clinicians usually think about prognosis in terms of physiology and treatment outcome, now they must also confront the fact that social behavior also influences prognosis.

For those who have seizures, epilepsy involves far more than seizure control and medication side effects. Epilepsy for them is a lived experience that can influence any and all levels of social life, from relationships with friends to obtaining employment.

Recent publications have begun to re-emphasize this social side of epilepsy: studies have concentrated on the experiences of people with epilepsy completely apart from the clinic (Schneider and Conrad 1983), or have moved between clinic and home (Trostle et al. 1983, West 1976, 1979). A recent collection presented the first detailed discussion of the causes of psychopathology in epilepsy that emphasized independent variables that are _social_ or _emotional_ (fear of dying, social class, stigma, locus of control) in addition to the more common clinical variables like seizure type, age at onset, or seizure frequency (Whitman and Hermann 1986).

The growth of epidemiology in the past few decades has added another perspective to epilepsy research. Epidemiologists have successfully shown that clinical cases cannot be used to generalize about incidence rates, prevalence rates, and risk factors in communities. Most epidemiological studies have been applied to the clinician's agenda, looking at types of epilepsy, risk factors, and prognosis, and evaluating treatments. But now the pitfalls of using clinical case series to generalize about social adjustment, psychopathology, and other non-biological issues are being made clear (e.g., Zielinski 1986), and epidemiological methods are becoming used more widely. This dissertion is one example of how epidemiological methods can be used to examine non-biological issues.

Project origins

This project was designed to resolve issues first raised during an anthropological study of epilepsy I completed in New York City in 1980. The New York study was designed to provide information about the variety of ways that people manage epilepsy. A literature review completed as part of the 1980 study showed that little in-depth work had been done on this topic; that which had been done consisted primarily of surveys of hospital or clinic populations (Bagley 1972, Shope 1978, Dodrill et al. 1980), or exploratory studies of foreign or ethnic minority groups not comparable with the majority of the U.S. population (e.g., Mulder and Surmeijer 1977 among Dutch; Peters 1978 among German; West 1976, 1979 among British; Neutra, Levy and Parker 1977 among Navajo). A sociological interview study of middle-class North Americans was still in progress in the Midwest among a self-selected sample of adults (Schneider and Conrad 1983), and an anthropological study of Black and Latino children in Los Angeles was being designed (Iverson and Scrimshaw 1983); these were the only relevant studies of which I was aware.

In concert with an anthropologist (Ida Susser) and a neurologist (W. Allen Hauser), who served as consultants, I conducted detailed, long-term observational research among people with epilepsy in New York City. The project was designed to study a small sample of people intensively; we purposefully sacrificed frequency counts and generalizability for breadth of knowledge and validity of descriptions. My goal was to find about ten people with epilepsy willing to have me visit them periodically over the course of a year to collect information about the daily process of dealing with a chronic illness. Thirty people were contacted through physician referrals, observations of epilepsy outpatient clinics, visits to epilepsy self-help groups, and advertisements in local newspapers, and each of them was interviewed. Eight people ultimately were willing to have an observer make repeated visits with them over the course of ten months. I went to their schools, accompanied them to medical appointments, ate in their homes, helped with schoolwork or fighting evictions or translating (some were Spanish-speaking immigrants from Puerto Rico or the Dominican Republic), and generally got to know them as individuals coping--or in some cases failing to cope--with epilepsy.

The study resulted in a paper called "The Logic of Noncompliance: Management of Epilepsy from the Patient's Point of View," in which Hauser, Susser, and I discussed the many varied ways that this heterogeneous group of people took care of themselves (Trostle et al. 1983). We described a number of different strategies of disease management, including various types of medication consumption strategies that did not agree with clinical prescriptions, but which made sense when the person's income, ethnicity, beliefs and values were taken into account. For example, an adolescent lower-class Puerto Rican anxious to appear healthy yet worried about possible addiction took his medications quite sporadically; a young middle-class Anglo woman who felt that her medication would calm her excited nerves and reduce the severity of her seizures took extra medication if she felt a seizure coming on; and a young Anglo man concerned about medication-related side effects consistently took less medication than was prescribed. We concluded that when the biomedical realm was seen as but one of a number of potentially conflicting health resources, then so-called "noncompliance" with treatment regimens could be seen as rational and even as justifiable behavior.

As the field researcher I witnessed the use of a number of different kinds of health resources to obtain treatment for seizures: the above-mentioned Puerto Rican adolescent was denied further appointments by a local hospital out-patient neurology clinic after he failed to attend three appointments in a row; when he wanted to get anticonvulsant medication he sometimes borrowed it from a neighbor who had seizures. In addition to seeing her neurologist the middle-class Anglo woman used a number of 'alternative' health resources, including biofeedback and megavitamin therapies. The middle-class young Anglo man went to a neurologist and a chiropractor, and sometimes followed the suggestions for calming nerves that he read in pamphlets in health food stores. We proposed that the study participants were more faithful to the search for an effective therapy than they were to the behavioral changes suggested by any particular therapy.

Our New York study described people in a particular urban community engaged in the day-to-day management of epilepsy, but could not conclude that the coping strategies described were either common or aberrant among other people with epilepsy. The study uncovered a broad range of concerns, motivations, and behaviors not normally visible or attended to in a neurologist's office; what remained was to study whether the kinds of concerns and behaviors we had seen over time in this small group were at all common among other people with epilepsy. Was this an extreme group with unique concerns and strategies? Did it represent other people with epilepsy in New York, other urban dwellers, or other people with epilepsy elsewhere in the country? We concluded the "Logic of Noncompliance" paper with calls for research on the history and philosophy of compliance, ethnographic work on chronic illness, and epidemiologic work that would focus on utilization of health resources. We called specifically for epidemiologic work because we felt we had been successful in describing a range of behavior among people with epilepsy, without describing the generalizability of this range. What remained was to augment our detailed qualitative description with quantitative estimates of the frequency of these responses and adaptive strategies in a larger, randomly selected sample.

To answer how common were the beliefs and actions, problems and successes observed in the New York sample I needed to look for a complete series of people with diagnosed epilepsy, from a defined population, for whom good medical records were available and among whom interviews could be done. Epidemiological work done at Mayo Clinic among the residents of Rochester, Minnesota had produced the most complete and best documented series of cases in any population-based study in this country; I therefore decided to do my study there. To avoid having too many different subgroups of respondents I decided to avoid schoolchildren and retired adults, and chose to study adults of working age (18 to 59). I reviewed medical records for all 199 adults in this age group that were prevalent cases of epilepsy in 1980, and interviewed 127 of them in the Fall and Winter of 1985. The setting and methods used in this study will be described more fully in Chapter Two.

Before turning to the substance of my study I will summarize the diagnosis, prognosis, and etiology of epilepsy, and contrast the etiological explanations of physicians with those employed by Rochester residents with epilepsy.

What is epilepsy?

Epilepsy, like other illnesses, has both medical and non-medical definitions, and both clinical and social ramifications. Neurologists define epilepsy physiologically, labelling it a chronic, episodic disorder of the central nervous system, characterized by seizures (Forster and Booker 1978). Seizures result from excessive electrical discharges in the brain, sometimes described as an "electrical storm" (Baird et al. 1977:5). These electrical discharges can be caused by many factors, such as acute infections, brain injuries, drug or alcohol withdrawal, high fever, insufficient levels of blood sugar or calcium, or electrical shock. Seizures are thus one of the body's natural responses to insult; all humans have a seizure threshold. Data from the community-based studies in Rochester, Minnesota suggest the lifetime risk of having one or more seizures of any kind is at least 8% (Hauser and Kurland 1975:58).

Seizures are relatively common events, but not all seizures are defined as "epilepsy": neurologists usually reserve the diagnosis for more than one seizure unassociated with other recognized illnesses of the central nervous system. Epilepsy *is* used to describe multiple seizures thought to result from abnormal functioning within the brain, for example, following a brain tumor or stroke. These are usually called "symptomatic" epilepsy, to distinguish them from "idiopathic" epilepsy that cannot be linked to any brain pathology or other cause.

The division between symptomatic and idiopathic epilepsy is based on the assumed etiology of the disorder. Neurologists classify seizures by where in the brain the electrical discharges begin, and whether consciousness is impaired. Seizure classifications have changed over time, but there are now two main categories: partial and generalized. *Partial* seizures begin in part of one cerebral hemisphere, and are classified as *simple partial* if consciousness is not impaired, and *complex partial* if consciousness is impaired. Partial seizures are contrasted with *generalized* seizures, which begin in both hemispheres, and therefore manifest themselves on both sides of the body. The major divisions within generalized seizures are *absence* seizures, which involve brief lapses of consciousness, and *tonic-clonic* seizures, which are convulsions of the whole body. Complicating the issue of classification is the fact that abnormal electrical activity can begin in part of the brain but then spread--seizures like these would be classified as *secondarily generalized*. This progression is sometimes visible, as when seizures begin in one extremity, then progress to involve the rest of the body. Other times the progression can only be measured with an electroencephalograph, which records types and locations of electrical activity within the brain.

Clinicians disagree about how to classify epilepsy--the process is sufficiently complex to make some researchers speak of "the epilepsies" instead of "epilepsy" *per se*. The classification of epilepsy has changed in the past, and continues to change in the present. For example, seizures were formerly divided into *petit mal* and *grand mal* types, whereas today each of these terms--still common in popular discourse--has been replaced in the neurological terminology by more complex categories. What is significant about the evolution of the epilepsy taxonomy is that seizure categories maintain their reified status despite being re-classified. Naming an illness often gives the illusion--to doctor and patient alike--that it is understood. Some people even say they have "idiopathic" seizures, as though the name "idiopathic" described some particular cause rather than an unknown etiology. The next sections on diagnosis, prognosis, and etiology will further explore these differences between biomedical and lay understandings of epilepsy.

The social definition of epilepsy is based on appearance rather than brain function. People in this country who have been exposed to some first aid or other training might differentiate between <u>petit mal</u> and <u>grand mal</u> seizures, which correspond with absence and tonic-clonic types of generalized seizures. Partial seizures are only rarely classified socially as seizures, being more often called "tics," "tremors," and various types of mental illness. Literature is one source of these images: the book <u>Rusty's Story</u> (Gino 1986) is a harrowing account of a woman whose seizures were misdiagnosed as paranoid schizophrenia. George Eliot describes how the villagers decided what to call Silas Marner's lapses of consciousness:

> Some said Marner must have been in a 'fit', a word which seemed to explain things otherwise incredible; but the argumentative Mr. Macey, clerk of the parish, shook his head, and asked if anybody was ever known to go off in a fit and not fall down. A fit was a stroke, wasn't it? and it was in the nature of a stroke to partly take away the use of a man's limbs.... But there might be such a thing as a man's soul being loose from his body, and going in and out, like a bird out of its nest and back... (Eliot 1967 [1861]:55)

Mr. Macey denies Marner has "fits," because Marner does not fall down. This is akin to the common misconception that the word epilepsy applies only to generalized convulsions. This social diagnosis of Marner's condition attends to his physical appearance, and gives emotional and spiritual forces a prominent causal role. It demonstrates a process of differential diagnosis, though the terms, definitions, and range of possible causes are all quite different from those employed by today's medical personnel. These differences will be explored in the following section on diagnosis.

Diagnosis

For patients and physicians alike, epilepsy is a condition filled with uncertainty. Diagnosing epilepsy is complex and time consuming: among 516 cases of epilepsy first diagnosed in Rochester, Minnesota between 1935 and 1967, half had a delay of more than six months between the first symptoms in the medical record and the first diagnosis, 30% had no diagnosis within two years of first symptoms in the record, and 15% still had no diagnosis within five years (Hauser and Kurland 1975:61). Many factors contribute to this delay: people may not know they are having seizures, label their symptoms as anything more than a minor problem, or seek treatment. The diagnosis may be delayed by physician uncertainty, by referrals to other physicians, or ambiguous test results. Diagnostic procedures rely on neurological exams, electroencephalography, and a variety of types of brain scans, but the patient history still provides the most important piece in the puzzle. Patient reports are crucial for establishing the age at onset of seizures, distinguishing simple from complex seizure symptomatology, and establishing possible causes of seizures. Physicians also may delay diagnosing epilepsy to assist their patients in obtaining work, or to avoid the stigma associated with the disease.

Diagnosis, when it finally occurs, leads not to an ultimate resolution of the disorder (the cure), but rather to long-term ongoing social and medical management (care). Naming the disorder is just the beginning. Both patient and physician face technical uncertainties in diagnosis, treatment, and prognosis. The patient also faces the uncertainty inherent in the condition itself: the frequently unpredictable occurrence of seizures. Being a patient means receiving medical treatment, but patients also have more encompassing roles as spouses, employees, parents, and friends. A diagnosis of epilepsy affects these roles by exposing people to potential legislative sanctions (loss of driving privileges, exclusion from certain occupations), as well as social stigma and uncertainties about rehabilitation.

One concern physicians have in diagnosing epilepsy is to distinguish between seizures that arise from organic and psychogenic precipitants. This has been a documented problem for physicians at least since the Hippocratic era, as Veith points out in her book Hysteria (1965:13). "Hysterical" seizures were in the 17th and 18th centuries culturally accepted forms of behavior in the Western world, but they became less common in the late 19th century as they were labelled "conversion symptoms," expressing emotional rather than physiological problems. So-called hysterical seizures may still be fairly common among people with epilepsy, with some authors estimating that as many as 10% of chronic cases have mainly psychogenic seizures (Goodridge and Shorvon 1983:643, citing Reynolds and Trimble 1982).

While the separation between seizures "of the body" and seizures "of the mind" reflects the classic Cartesian dualism of Western biomedicine, it does have important implications for the choice of treatment. Separating mind and body makes sense when their recommended therapies are polarized: mind therapy (psychotherapy) has many fewer side effects when compared to body therapy (anticonvulsant medications or surgery). Reports have documented psychogenic epileptiform seizures diagnosed and treated inappropriately as epileptic seizures for as long as four years (Gross 1979--cases are also documented in Finlayson and Lucas 1979, Roy 1977, and Williams et al. 1978). Investigators also have found that some people have seizures of both types. Most epidemiologic studies of epilepsy are careful to separate these different types of seizures--even the large proportion of seizures called "idiopathic" still includes no seizures known to be only psychogenic.

The epidemiology of epilepsy

The epidemiology of a disease is the study of its distribution and determinants. Distribution is commonly described by incidence and prevalence: incidence rate is the number of people who first acquire a disease within a specified time period, compared to a specified population at risk of acquiring the disease, while prevalence rate is the number of people who actually have a particular disease at a specified point in time, compared to a specified population at risk.

Studies of the distribution of seizure disorders have produced conflicting results and few firm conclusions about variations in prevalence aside from age- and sex-specific distributions. Almost all reports of incidence and prevalence rates suggest men are more commonly affected than women. The overall mean annual incidence of epilepsy in Rochester from 1935 through 1967 was .52 per 1,000 for men, and .46 for women, with a combined rate of .49. Almost all studies show highest incidence rates in the first year after birth, decreasing for successive age groups, while some show an additional peak after age 60. The Commission for the Control of Epilepsy and Its Consequences (Vol. 4, 1978), Hauser and Kurland (1975), Hauser (1978), Leviton and Cowan (1981), and Neugebauer and Susser (1979) give detailed reviews of the variability among studies.

Most researchers conclude that a conservative estimate of the annual incidence of epilepsy is about .30 to .50 per 1,000 population, while the prevalence of active epilepsy is about 6.5 per 1,000. (Active epilepsy is usually defined as taking medications or having a seizure within five years, though some authors use a two year period.) Assuming the total U.S. population is about 240 million, there are about 1.5 million people with active cases of epilepsy, and about 72,000 to 120,000 new cases each year.

Some studies suggest higher rates of seizure disorders among the lower social classes; however, such data usually have been collected from studies of medical records rather than from community surveys, and therefore may reflect differences in rates of service utilization and other ascertainment biases rather than true rates of seizure morbidity (Neugebauer and Susser 1979:208-9, Leviton and Cowan 1981:72-3). A recent community-based study in Los Angeles found age-adjusted prevalence rates of 13 per 1,000 for blacks and 8.1 per 1,000 for Hispanics, but these preliminary figures did not control for social class, which might also be contributing to the higher rates (Locke et al. 1986). Seizure rates also may be higher in developing countries than in industrialized ones (Cruz et al., 1986), but this conclusion is complicated by the many differences among studies in the ways seizures are defined, discovered, and counted. Some studies count febrile seizures while other exclude them, some include single seizures while others require multiple, some use school or hospital records while others do community surveys.

Variations in incidence and prevalence rates for people with epilepsy depend partly on the source of the cases, and partly on the willingness of people to disclose their condition to interviewers or physicians. The accuracy of prevalence rates depends on complete enumeration of cases, but some epidemiologic studies have suggested that significant proportions of people with epilepsy never have and never will receive medical care for their seizures, that some people who have been diagnosed in the past will fail to reveal the diagnosis in the present, and that people will of their own accord stop taking medications and eventually become inactive cases. Zielinski compared the incidence and prevalence of epilepsy in Warsaw, Poland, using service-based and community-based samples, and discovered that almost one quarter of those in the community study had never consulted a physician about their seizure disorder, and another 15% had stopped medication of their own volition (Zielinski 1974, 1976). Beran et al. (1985b) found that among respondents in Sydney, Australia who had diagnoses of epilepsy in their clinic records, 23% denied the diagnosis on a questionnaire. Beran et al. (1985a) argued that prevalence studies of epilepsy must therefore adjust both for untreated and diagnosed but undisclosed cases; they concluded that the prevalence of epilepsy in Australia is about 20 (rather than 6.5) per 1,000.

Prevalence studies based on medical records are not affected by the "diagnosed but undisclosed" group, since diagnosis appears in the medical record. Two groups still may not be accounted for by this method: a small number of people with prior diagnoses of epilepsy will never reveal the diagnosis after migrating to a new area; and another group of people of unknown size will never bring their seizures to medical attention, either because they do not feel the seizures are important, or they are afraid or otherwise reluctant to be diagnosed and treated. It is debatable whether this last group should be included in health-related statistics: if they have never sought nor been brought to medical medical attention their seizures probably do not interfere with their everyday lives; on the other hand, this may bias the clinical picture of epilepsy since it excludes the minor types of brain dysfunction. While the question cannot be resolved theoretically, it can be answered practically:

prevalence figures are used primarily to estimate the medical, economic, and behavioral impact of a condition, therefore it seems appropriate to use prevalence figures uncorrected for undiagnosed cases. This caveat needs to be remembered, however: most of the discussions of epilepsy are necessarily based on cases that have received medical attention and/or treatment.

Prognosis

A prognosis is a judgment about the future course and likely outcome of a disease. People who have had a single seizure face questions such what caused it, whether it should be treated, and whether it is likely to recur. People who have had more than one seizure must ask how long they will be subject to more, whether they should be treated, whether their treatment is effective, and when it should be stopped.

The word prognosis has a clinical aura, but there are both clinical and social prognoses for epilepsy. The clinical prognosis of epilepsy refers to the likelihood of future seizures, and depends on factors like seizure type, age at onset, number of seizures before treatment, cause, presence of other neurological impairments, and family history of seizures. Clinical prognosis itself is interpreted by patients, so there is a social aspect to the clinical prognosis, referring to people's perceptions of the likelihood that they will have more seizures. The social prognosis of epilepsy refers to the likelihood of outcomes such as impaired employment, social isolation, and emotional problems. It depends on the clinical factors just mentioned, as well as factors like parental reaction, social class, educational attainment, and adjustment to seizures.

Epilepsy differs from some illnesses in that its course is unpredictable. Assessing its course is complicated by the fact that seizure medications do not control symptoms like a cough or skin rash, but control possibilities: episodic seizures. Some people have seizures despite taking medications, but would have more if they stopped medications; others would have seizures only if they stopped taking medication; still others would not have seizures even if they stopped taking medications. Starting medication thus makes it impossible to measure the complete "natural course" of seizures.

Nonetheless, studies in the last decade have estimated a number of aspects of the natural course of epilepsy: the likelihood of having additional seizures after having had one (recurrence), having extended periods without seizures (remission), and having seizures recur after remission (relapse). These studies have given varied estimates. What is the risk of having a second seizure, and thus getting labelled as having epilepsy? Recurrence after one is most likely within the first few months, and the probability of seizure recurrence goes down with time since seizure. A person who has had one idiopathic seizure, and gone one year without any more, has a 10% to 25% chance of having more seizures over the next few years. One estimate of the cumulative recurrence risk is 16% at one year after a first seizure, 27% at three years, and 34% at six years (Hauser et al. 1982, 1986. A second estimate of the cumulative risk is somewhat higher: 36% at one year after a first seizure, 48% at three years, and 56% at five years (Annegers et al. 1986). The risk of having a subsequent seizure is higher among those whose initial seizure was symptomatic. Among those whose first seizure was idiopathic, seizure recurrence was associated with EEG abnormalities, a history of neurological deficits from birth, an abnormal neurological exam, and a partial seizure. Age, sex, and a history of a metabolic or trauma-related seizure have not consistently predicted recurrence.

All studies show that high proportions of people who are said to "have" epilepsy also have long intervals without any seizures. Approximately 65% of diagnosed cases of epilepsy will have had a five-year period of remission within ten years of their diagnosis, and 76% within 20 years of diagnosis (Annegers et al., 1979). Yet if the condition "epilepsy" is defined as "having more than one seizure in the absence of a specific precipitating organic condition," then the diagnostic label can be applied to cases long after the last outward manifestations of the condition (seizures) disappear. This difference is seen in the varying estimates of prevalence rates when based on active cases or on ever-diagnosed cases (the latter is commonly called "cumulative" or "life-time" incidence): cumulative incidence rates are higher than active prevalence rates precisely because seizures remit. But this raises an important labelling question. Some have argued that once a person has had two or more seizures, he or she is always liable to have more--thus they say "once an epileptic, always an epileptic" (described in the Commission for the Control of Epilepsy, Volume 4, 1978:82). What are the social ramifications of this? When is it no longer necessary to take medication, and when does the diagnosis no longer apply? These are important questions that are just now beginning to receive proper research attention.

The Rochester study did provide some information about the social perceptions of prognosis. We asked interviewees how likely it was that they would have seizures in the future: 60% of 125 respondents said they thought it was not at all or not too likely, and 40% said it was fairly or very likely. If individual perceptions of risk agree with epidemiologic measures of risk then perceived likelihood of future seizures should be greatest among those with recent seizures. This is exactly what happened: Table 1.1 shows that estimates of seizure likelihood went up as mean years since last seizure went down. For clinical prognosis, individual assessments of future risk agree with the epidemiologic evidence.

Table 1.1
Recency of last seizure by perceived likelihood of future seizures.

Seizure likelihood		Mean years since last seizure
Not at all likely	(34%)	10.9
Not too	(26%)	7.4
Fairly	(18%)	3.7
Very	(22%)	3.5

(ANOVA F=11.55, d.f.=3,121 p<.0001)

The prognosis for epilepsy does not depend solely on the likelihood of future seizures. Since seizures are episodic, taking anticonvulsant medications is just as emblematic of the continuing existence of epilepsy as seizures are. It has been estimated that 40 to 50% of cases can completely control their seizures with anticonvulsants (Mattson et al. 1985). But social concerns also affect the pharmaceutical control of seizures: the figure of 40 to 50% controlled assumes that medications will be prescribed and taken properly, but studies have found nontherapeutic anticonvulsant levels in 26 to 97% of cases (Trostle et al. 1983). Chapter Four will explore how residents of Rochester viewed taking medications over time: for some, medications are the last remaining reminder that some potential illness exists; for others, medication is the only protection from the threat of resumed seizures.

There is much to be discovered about the epilepsies, but I do not mean to suggest that the diagnosis of epilepsy leaves a person without recourse or hope. As mentioned above, significant proportions of people with epilepsy will have long remissions from seizures. And even if seizures do recur, their potential to do emotional and social damage largely depends on the attitudes and support given by friends, family, and society. These attitudes and their effects will be reviewed in Chapter Five.

Cause

Anthropological interest in disease causation has an extensive history (see Gillies 1976 and Worsley 1982 for reviews). Anthropologists make an important distinction between causal frameworks which rest on ultimate explanations (why a particular disease, accident, or injury has happened to a particular individual), and causal frameworks which rest on immediate explanations (how a particular disease, accident, or injury has occurred) (Evans Pritchard 1937, Horton 1973, Nydegger 1983).

The distinction between immediate and ultimate causes applies to epilepsy (Trostle et al. 1983). Immediate causes, or seizure triggers, are events or circumstances which are thought to precipitate particular seizures, while ultimate causes are events or circumstances that explain why one is subject to having seizures in the first place. This is akin to the difference in epidemiology between a predisposing and a precipitating cause (see, e.g., Cassel 1976 for this distinction).

Although respondents and physicians both appear to agree that the prognosis for future seizures depends on the recency of past seizures, they do not agree on the causes of their epilepsy. When looking at the ultimate cause of epilepsy, or the immediate cause of particular seizures, people with epilepsy gave quite different reasons from those given by neurologists.

Contemporary neurologists are able to assign causes to epilepsy in only a limited proportion of cases. In the Rochester, Minnesota case series, causes of epilepsy were identified in only 23% of 516 cases first diagnosed during 1935 through 1967 (Hauser and Kurland 1975:30). Thus some 75% of cases are "idiopathic," or without a cause ascribed by biomedicine. Some evidence does suggest a role for the genetic transmission of epilepsy, though that role is far less important than it was thought to be at the height of the eugenics movement early in the century. Contemporary estimates of the risk of epilepsy for a child or sibling of a proband with epilepsy is 6-8% (Hauser et al. 1983:289). Seizure recurrences also are more frequent among those having a sibling with seizures compared to those without an affected sibling (Ibid.). Finally, a history of febrile seizures increases the risk of having epilepsy three- to sixfold above the population rates (Ibid.:279).

In discussing the various health resources and methods utilized by our informants it became clear that most people had selected one or more ultimate causes for their seizures despite the fact that outside neurologists reviewing their records could not assign any ultimate causes to their epilepsy. One or more ultimate causes were mentioned by 68% of 127 respondents, while 32% said they did not know a cause. (Two of these respondents specifically said their seizures were "idiopathic.") The results of categorizing all responses together can be seen in Table 1.2. The most common response was to say the cause was unknown (26% of responses). Physiological or anatomical causes (for example, brain tumors or lesions, puberty, birth defects) comprised 22% of responses, physical trauma (especially head injuries) another 19%, infections 14% (febrile illnesses, encephalitis, meningitis), psychological trauma or stress 8% (seeing another person have a seizure, having too much work), genetic factors 8% (having a close relative with seizures), alcohol consumption 3%, and environment insults (noxious smells) 1%.

Table 1.2
Etiology of epilepsy as perceived by respondents:

	#	% of 159 responses
Unknown	41	26
Physiological/anatomical	35	22
Physical trauma	30	19
Infection	22	14
Psychological stress	12	8
Genetic	12	8
Alcohol consumption	5	3
Environmental insult	2	1
Total:	159	101% (due to rounding)

These reasons differ from the prevailing medical judgements about seizure etiology. I said before that physician epidemiologists could assign causes for only 23% of Rochester residents who had epilepsy. (This decision was separate from the assessments made by each person's physician.) Looking only at the people who were interviewed, epidemiologists found causes for 14% of 125 cases (2 cases had missing data). These causes are listed in Table 1.3. When compared with the preceding table large differences can be seen between the etiologic judgements of interviewees and epidemiologists.

Table 1.3
Etiology of epilepsy as perceived by physicians:

	#	% of 125 cases
Idiopathic	107	86%
Vascular hemorrhagic	3	2
Physical trauma	4	3
Infection	5	4
Brain tumor	1	1
Degenerative	2	2
Developmental	3	2
Total:	125	100

Interviewees and epidemiologists often disagreed in their labels, but their differences did not appear randomly distributed. Table 1.4 shows the differences among the etiologic categories. Because respondents could give more than one answer, this table compares each respondent answer with the etiologic label assigned to that respondent by physician epidemiologists. Only about one third (34%) of classifications matched, with most agreement occurring on the idiopathic category since it was most commonly employed both by interviewees and physicians. To lessen reliance on the physician's very specific categories, and increase the chances for a match, categories were collapsed into idiopathic, infectious, and "body-related" causes. The "body-related" category combines trauma, physiological, and anatomical causes. (If, for example, a respondent with epilepsy which the physician said was caused by a vascular hemorrhage said his seizures were caused by circulation problems, this still allowed the categories to match.) Mismatches between physician and interviewee categories can be categorized according to either standard. Among cases that physicians labelled as idiopathic, about one quarter (27%) of the 133 responses matched this label. Among cases that physicians labelled infectious, two-thirds of nine responses matched. Among cases that physicians labelled with one of the four "body-related" categories, about three quarters (71%) of 17 responses matched.

Higher proportions of mismatches were found using respondent categories as the standard, but this is because so many respondents mentioned ultimate causes where physicians could find none, and because the biomedical categories of etiology exclude some of the respondent categories such as psychological stress, genetic factors, or alcohol. Among respondents who attributed their seizures to no known cause, only 12% of responses were not labelled idiopathic by physicians. Among those who attributed their seizures to infection, 73% of responses were not so labelled by physicians, and among body-related responses, 81% were not matched.

Table 1.4
Comparisons of causal categories between physicians and respondents

Labels	Frequencies	
Idiopathic by physician and respondent:	36 of 133 responses[1]	(27%)
Infectious by physician and respondent:	6 of 9	(66%)
Body-related[2] by physician and respondent:	12 of 17	(71%)

Total matching classifications:	54 of 159 responses	(34%)
Idiopathic by physician but not respondent:	97 of 133 responses	(73%)
Infectious by physician but not respondent:	3 of 9	(33%)
Body-related by physician but not respondent:	5 of 17	(29%)
Idiopathic by respondent but not physician:	5 of 41 responses	(12%)
Infectious by respondent but not physician:	16 of 22	(73%)
Body-related by respondent but not physician:	53 of 65	(81%)
Psychological by respondent but not physician:	12 of 12	(100%)
Genetic by respondent but not physician:	12 of 12	(100%)
Alcohol by respondent but not physician:	5 of 5	(100%)
Environmental insult by respondent but not physician:	2 of 2	(100%)

Total non-matching classifications:	105 of 159 responses	(66%)

[1] Respondents could give more than one cause.

[2] Body-related classifications are grouped: respondent categories of physiological/anatomical or physical trauma are compared with physician categories of vascular, physical trauma, tumor, degenerative, and developmental causes.

Where physician epidemiologists were able to select etiologic causes for epilepsy, respondents often provided similar causes. But even where no etiologic cause was found by external physician review, most patients nonetheless selected a cause. The kinds of causes they selected (mostly infectious and body-related) were drawn primarily from the set of causes of epilepsy that are recognized by physicians. (For example, no respondents mentioned spiritual causes of their epilepsy.) Only a small proportion of respondents mentioned ultimate causes (genetic, psychological, alcohol, other) that were not used as etiologic categories by physicians. One of these categories, genetic causes, could easily have been mentioned by physicians: most physicians would probably say that they "could not rule out" a genetic cause, but this may prompt patients to infer that they should "rule it in."

In sum, a variety of ultimate causes were mentioned by respondents whose epilepsy was labelled idiopathic by some physicians. These causes were largely drawn from classic biomedical categories of etiology: illness, trauma, physiologic problems. When exploring the reason for their epilepsy, respondents were reluctant to accept "no cause" for an answer. It appears that these respondents were using biomedical categories as an idiom to express their own beliefs and concerns about why they were subject to having seizures, providing certainty even when their physicians would not.

A somewhat different picture emerged when Rochester residents were asked about the triggers of particular seizures rather than the original cause of the epilepsy. Physicians could assign a cause to the epilepsy of only 14% of respondents, but 80% of respondents gave reasons for having particular seizures. People again gave many reasons--256 were mentioned in all--but these immediate causes often were not as directly based in biomedical categories as were the ultimate causes they mentioned, suggesting disparities between respondents and physicians on this aspect of etiology. Only 12 respondents mentioned psychological factors as the ultimate cause of their epilepsy, but 69 respondents mentioned psychological factors as immediate causes for particular seizures. Table 1.5 shows that respondents most commonly linked seizures to stress or emotions, sleep deprivation, tiredness, or nothing at all. Smaller proportions attributed seizures to missed medication doses or low medication levels in the blood, to light, physical exertion, diet, drugs or alcohol, or other illnesses.

Table 1.5
Immediate causes of seizures as perceived by respondents

	#	%
Stress or emotions	69	27
Sleep deprivation	32	13
Tired	25	10
Nothing	25	10
Miss medications or have low levels	18	7
Menstrual period	12	5
Lights/sunshine	12	5
Alcohol or drugs	11	4
Diet	8	3
Physical exertion	8	3
Other illness	8	3
Other (none more than 1%)	25	10
Don't Know	3	1
Total:	256	101% (due to rounding)

Contemporary evidence in addition to that from Rochester shows that persons with seizures, and their families, have varied etiological beliefs about their epilepsy. Voeller and Rothenberg comment on the large number and significance of these concepts among 266 patients and their families selected from the pediatric seizure clinic of a general hospital in New York:

> Parents have remarkably varied and naive fantasies regarding the causality of seizures. These thoughts are characteristically not communicated to the physician (who usually assumes that the parent either has no thoughts on the subject or accepts prevailing medical explanations). (Voeller and Rothenberg 1973:1073)

Tavriger quotes the 19th century neurologist Hughlings Jackson as suggesting that such reasons are necessary "because the patient is apparently healthy: there is a 'tendency to fall back on the nearest most striking event--fright, temporary dyspepsia, overwork'" (1966:339). This is certainly one of epilepsy's most striking characteristics: given its episodic occurrence, a person who appears to be quite normal at one moment will suddenly in the next moment behave quite abnormally, and will appear to have lost all control. It is difficult for observers to accept such extremes of behavior, and difficult for the observed to respond to the reactions of the observers. Perhaps it is yet more difficult for all to accept that these behavioral extremes cannot always be linked to known external precipitants. Where physicians are unable to provide reasons, patients are likely to provide their own.

Tavriger's (1966) interviews in England with parents of 118 children who had epilepsy found over one-third reported at least one and sometimes many theories of seizure causation. The most frequently mentioned cause was prolonged psychological stress. Voeller and Rothenberg (1973) and Tavriger (1966) have also mentioned a tendency among some of their middle class interviewees to see epilepsy as "nerves". Mulder and Suurmeijer (1977) in the Netherlands, Schneider and Conrad (1980, 1983) and Trostle et al. (1983) in the United States, and West (1979) in Great Britain have presented confirming evidence of this variety in seizure classifications, using more detailed etiological accounts based on smaller sample sizes.

Patients develop their own etiologic classifications, and these classifications have real influence on the kinds of resources that are used for treatment. For example, the concept of "nerves" has a powerful ambiguity, since it applies both to anatomical structure and to psychological stress. Epilepsy is described as a disorder of the nervous system, and is therefore thought by some to be caused by nerves defined in this broader sense. (For example, one respondent said he had epilepsy because he couldn't "get my nerves under control," another wrote that his epilepsy was caused by "a bruised nerve in the brain tissue.")

Classifying epilepsy as a condition of nerves rather than of brain makes it amenable to treatment by resources that specialize in nerves, such as a chiropractor. This is one reason why people with epilepsy sometimes choose chiropractors to treat them. Another reason is that some chiropractors themselves emphasize the connection between epilepsy and nerves, as did one Minnesota chiropractor who advertised acupuncture as a quick cure for epilepsy. The text of his advertisement follows:

> Epilepsy is a disorder marked by disturbed electrical rhythms of the central nervous system and is typically manifested by convulsive attackes (sic) usually with clouding of consciousness. Over the last 17 years I have had outstanding results using acupuncture treatment for epilepsy. Many times these patients will completely recover after several months of care. ...Reduction of the convulsive attacks will usually occur within two weeks.

A similar approach was seen in the course of my New York study, where I accompanied a person who had epilepsy to his chiropractor's office:

> One patient's testimonial in a printed newsletter [in the office] stated that a child's convulsions 'were not as hard' after the child began chiropractic treatments; it added that this child could be 'brought out' of the convulsions by a pressure point indicated by the chiropractor" (Trostle et al. 1983:50).

But variety in etiological beliefs should not be assumed to be uniquely associated with epilepsy: similar accounts exist for North Americans classified by ethnic group (e.g., Harwood 1971, 1981, Snow 1974), by residence (Mabry 1964), and by diagnosis (e.g., for arthritis, Elder 1973, Kronenfeld and Wasner 1980; for polio, Davis 1963; and for multiple sclerosis, Stewart and Sullivan 1982). Etiologies help explain how diseases occur, but they also satisfy individual's needs to explain why they have been singled out to bear some particular misfortune.

Epilepsy occupies a unique status within the variety of possible diseases known to humankind. Seizures are thought to originate variously from body, brain, mind, emotion, and spirit. They are unpredictable, and thus demand to be managed. In fact one could speak of an "architecture of unpredictability" that must be employed by people with epilepsy to order and make sense of their world. This architecture uses cultural beliefs about what forces are at work, what outcomes are possible, which outcomes are desirable, and how they can be attained. Chapter Two describes the setting and methods of the Rochester study that I have referred to briefly in this chapter. Chapters Three and Four on medication and service use explore how the beliefs of the medical profession and Rochester respondents affect the management of treatment regimens. Chapters Five and Six on stigma and bureaucratic sanctions explores how cultural rules, professional beliefs and practices, and interviewee beliefs and experiences affect how Rochester residents with epilepsy manage their identity as persons with a chronic episodic health problem.

CHAPTER TWO: SETTING AND BACKGROUND

Empirical data cannot be understood apart from their context. This chapter describes why Rochester has become an important site for population studies of disease; how these studies, especially those of epilepsy, are usually done; and how my study was carried out there. I evaluate a number of possible sampling biases, and conclude that the people I interviewed represent in most respects the population of adults with epilepsy in Rochester. Whether my results are generalizable to other areas of this country depends on how one assesses the similarities of Rochester to other U.S. cities. Rochester results are most easily generalizable to other white, middle class, and well-educated populations. It is a town dominated by medical industry, and thus gives minimum estimates of the problems that would be encountered in populations having fewer medical resources.

Setting

Rochester, Minnesota, best known as the home of the Mayo Clinic, is a town of some 60,000 inhabitants in the southeastern corner of the state. In some ways it is like other small midwestern towns, and in some ways it is unique. Agriculture surrounds Rochester: the town rises above the corn fields that border it on all sides, and a local vegetable canning plant's watertower has been constructed and painted to resemble an ear of corn. The local news media follow farm commodity prices closely. Front page stories in 1985 frequently discussed farm foreclosures, the governor's latest proposal for agricultural subsidies, the strike at a meat packing plant in a nearby town, and the future of agricultural exports. Medicine forms a significant part of the local economy, but is not the only business in town: driving into Rochester from the north one passes a large IBM plant started in 1956, which in 1985 employed about 7,500 people. Other Rochester employers of more than 250 people in 1985 included a large hotel, the school district, the above-mentioned vegetable packing plant (in season), the Olmsted County government, a sheet metal fabricating plant, the city government, a food store, and a dairy. Other major town institutions include a state community college with 3000 students, and vocational school with 1400 students.

Though agriculture dominates Rochester's borders, medicine in the form of Mayo Clinic buildings dominates Rochester's skyline. The Mayo Building, last expanded in 1969, is a 19 story stark white marble-clad tower. It adjoins the Plummer Building, opened in 1928, an elaborate 15 story building topped by a tower and carillon. Beside the Plummer building is a large hotel, next to that the modern brown and black buildings of the Mayo-affiliated Rochester Methodist Hospital, and a few blocks from that a tall nursing home. One half mile west of the main Clinic buildings lies Saint Marys Hospital, the larger of the two hospitals affiliated with the Clinic. Shuttle buses scoot back and forth between the Mayo Building and Saint Marys Hospital about every five minutes during working hours. On weekends the downtown Clinic buildings close, and the downtown area becomes the preserve of local shoppers and hotel guests.

Streets are wide in Rochester, perhaps to give the plows a place to pile the snow in winter. The downtown retail area occupies about 6 blocks, consisting of a standard array of stores supplemented by a few extra gift shops and restaurants. As elsewhere in America much of the town's life is now centered in a number of covered malls on the outskirts of town. While a new cinema complex in one of the malls runs six movies simultaneously, there are two vacant cinemas downtown.

Rochester has grown and adapted to the needs of those who come to the Clinic: there were 48 hotels and motels in town in 1985, with more than 5700 rooms to serve the approximately 600,000 visitors who arrive each year. Rochester's airport has more than 30 commercial jet flights each day. The crossing lights on the streetcorners seem designed to accommodate to visitors' needs: they blink yellow for minutes, allowing the infirm to cross without hurrying--and the foolish to cross three times. Hotels as close as three blocks from the clinic advertise their willingness to provide free roundtrip transportation. (Even the healthy take advantage of this service when the temperature is 20 degrees below zero.)

Demographics of Rochester

Rochester has been a Standard Metropolitan Statistical Area for the U.S. Census Bureau since 1970, facilitating demographic descriptions. Table 2.1 summarizes the figures on schooling, nativity, ancestry, and income from the 1980 Census: Rochester's inhabitants are affluent (median family income over $23,000, less than 4% of families below the poverty line), well-educated (84% high school graduates, 29% college graduates), and of Northern European ancestry (97% White).

TABLE 2.1
INCOME, SCHOOLING, NATIVITY, AND ANCESTRY OF ROCHESTER RESIDENTS
(from Rochester SMSA 1980 census information)

Total population: 57,890

Median family income: $23,505

6.8% of persons below poverty level
3.5% of families below poverty level

Schooling: (persons 25+)
83.9% high school graduates
21.2% some college (1-3 years)
29.0% 4+ years college

Residence in 1975 (among those 5 years or older)
71% within Rochester SMSA

Nativity: 96.6% native (64.5% born in MN)
3.3% foreign born

Ancestry: 79% of 25021 who claimed one ancestry group were English, German, Irish, Norwegian, or Swedish

97.4% (56408) of total (57890) were listed as White
1.3% (760) Asian
0.6 (351) Black
0.6 (371) Other

(0.8 [463] of above listed as of Spanish origin)

Rochester's unemployment rate is lower than that of the whole state (3.7% in 1980 when the statewide average was 6.2%, and 3.7% in September, 1985 when the statewide average was also 6.2% [Rochester Post-Bulletin 11/20/85].) The occupations in Rochester reflect the importance of IBM and Mayo: Table 2.2 shows they are largely concentrated in the professional (22%), service (17%), and administrative support (16%) categories. These employment opportunities help to shape the demographic profile: the 1980 census showed Rochester's age/sex profile to resemble other American towns, with the exception of a relatively high proportion of women aged 20 to 24 (Tables 2.3 and 2.4). These women come to Rochester to work as clerks, technicians, nurses, and other service-related occupations within the health services industry. Table 2.3 describes the age and sex structure of Rochester's population, with the high proportion of females visible in practically all age groups, but particularly prominent in the groups aged 20 to 24 and 65 and over.

TABLE 2.2
OCCUPATION OF ROCHESTER RESIDENTS
(from Rochester SMSA 1980 census information)

Occupation among 31062 employed persons 16 and over:

31.9%		Managerial and professional specialty
	10.0	Executive, administrative, and managerial
	21.9	Professional specialty
35.3%		Technical, sales, and administrative
	9.7	Technicians and related support
	9.3	Sales
	16.3	Administrative support, including clerical
16.6%		Service
	0.5	Private household
	0.8	Protective service
	15.3	Service except household and protective
0.4%		Farming, forestry, and fishing
7.1%		Precision production, craft, and repair
8.8%		Operators, fabricators, and laborers
	4.0	Machine operators, assemblers, and inspectors
	2.2	Transportation and material moving
	2.5	Handlers, equipment cleaners, helpers, and laborers

TABLE 2.3
AGE AND SEX OF ROCHESTER POPULATION
(data from 1980 census)

	FEMALES		MALES	
Age group	N	%	N	%
<20	8952	15.6	8719	15.1
20-24	4234	7.3*	2717	4.7
25-34	5743	9.9	5265	9.1
35-44	3463	6.0	3270	5.7
45-54	2609	4.5	2427	4.2
55-64	2344	4.1	1970	3.4
65+	4191	7.2*	1986	3.4
Total	31536	54.5%	26354	45.5%

* Large differences in sex ratios

Table 2.4
Comparison of 1980 Rochester SMSA with White Population of the U.S.

Characteristic		Rochester	United States
Sex:	% female	54.5	51.4
Age:	% >= 65 years	10.7	11.3
Education:	% >=12 years	84.0	70.5
	% >=16 years	28.8	17.8
Income:	Median family	$23,505	$20,439

Migration rates into and out of Rochester are somewhat high (28% of residents 5 years and older in 1980 had not resided in the Rochester SMSA in 1975) but these rates are largely accounted for by the movements of two groups of people: employees of IBM who are transferred into and out of

Rochester, and Mayo Clinic Fellows serving internships or residencies for two to three years at Mayo before moving to practice in other parts of the country (Hauser and Kurland 1975:11). In 1975 Hauser and Kurland estimated there were 700 Clinic Fellows, one third of whom finished their studies and were replaced each year. Many of these Fellows had families with young children. By 1985 there were almost 800 Clinic Fellows, and another 150 research fellows and visiting students.

In sum, Rochester is a town largely populated by middle class whites, with employment dominated by service industries. The demographic characteristics of the Rochester population are similar to those of the rest of the United States (Table 2.4), with the exception that a high proportion of the population are employed in health care, and thus have a relatively high level of education. A household survey done in 1974 showed that 10% of Olmsted County residents worked in health facilities, and 26% of households contained a person who worked in a health facility (Olmsted County Survey 1974:8). Results of population studies of disease in Rochester have been extrapolated to a large part of the U.S. population, but are probably not applicable to urban populations, minority groups, or the underprivileged. Behavioral studies of medical problems in Rochester must compensate for the presence of a large tertiary care medical facility.

Mayo Clinic

The Mayo Clinic and its associated activities distinguish Rochester from other American towns, for the Clinic was the first and is the largest group practice of medicine in the world. William Worral Mayo began practicing medicine in Rochester in 1863, and his sons William and Charles joined his practice in 1883 and 1888. The Mayo family specialized in surgery, and attracted many patients. They began to add additional members to their group: by 1907 there were 12 full-time physicians in the organization, which was run as a partnership owned by the Mayo family. In 1923 the partnership was turned into a group practice administered by a Board of Governors, and all staff were salaried (Clapesattle 1941). More than one million patients had been registered by 1938, two million by 1954, and three million by 1973.

The statistics describing Mayo Clinic are Texan in scale: in 1985 there were more than 14,000 staff at the Clinic and its two affiliated hospitals. The Clinic occupies 2.4 million square feet of space in nine downtown clinic buildings and has more than 1200 exam rooms. The two affiliated hospitals, Saint Marys and Rochester Methodist, have between them 1800 hospital beds and 80 operating rooms. Mayo has more than 800 staff clinicians (called consultants). In 1985 the gross revenue of the Clinic and hospitals was more than 650 million dollars. (Source: Mayo Facts 1985, a circular put out by the Clinic Office of Information.) Mayo is expanding its practice; it recently opened branch clinics in Scottsdale, Arizona and Jacksonville, Florida, and started a Health Maintenance Organization for Southeast Minnesota and Northeast Iowa.

The numbers describing the Clinic's clientele are as large as those describing its facilities. More than 3.8 million people have sought care there since records were first kept in 1907. More than 280,000 patients registered in 1985, and between 1 and 1.5 million patient-physician interactions took place that year. Patients have visited from all 50 states and more than 100 foreign countries.

While the Clinic draws patients from all over, more than half come from southern Minnesota and northern Iowa, and about three quarters come from Iowa, Minnesota, Wisconsin, and Illinois. (Chicago, Milwaukee, Des

Moines, and Omaha are all within 350 miles of Rochester.) The Clinic serves three main populations: local residents of Rochester and the surrounding area who can visit the Clinic and return home in the same day; residents of Minnesota and surrounding states who can reach Mayo within a day's drive, but who are likely to stay over in Rochester; and those who live farther away either in the USA or abroad. Local residents are in the relatively unique position of using a health service which also serves a wealthy international clientele. The Rochester newspaper commonly announces that a U.S. Supreme Court justice, an actress, a talk-show host, or a foreign dignitary is in town for his or her annual checkup.

Mayo's buildings effectively transmit an image of quiet luxury and competence. The Hilton Pavilion and Guggenheim Building were named after principal contributors. Maintenance staff in front of the Baldwin Community Medicine Building cut the grass in two directions, and then clip by hand the remaining wisps near the signs and sculptures. Public areas of the clinic have high ceilings, carpeted floors, and wood, marble, or glass walls. Waiting areas are spacious, with comfortable seating, indirect lighting, and live plants. Original works of art are displayed everywhere: one hallway contains "The Mayo Collection of Pre-Columbian Art," a Calder mobile hangs above a stairway, paintings and lithographs by Calder, Miro, and other modern artists hang near the pharmacy downstairs. Staff areas are less luxurious, but still quite comfortable and very well maintained. Mayo medical students tell a story about a repairman appearing only a few minutes after a secretary overheard the students complaining about a jammed locker door.

Mayo's size, prestige, and patient volume do have drawbacks: some Rochester residents feel they are treated impersonally at Mayo, and complain about long waits, rushed examinations, and rotating staff. It was partly to satisfy these complaints that the Olmsted Medical Group (now Olmsted Medical and Surgical Group, OMSG) was started in 1955 by three local general practitioners not affiliated with Mayo. They also started and staffed the Olmsted Community Hospital (OCH) in that same year. (In 1985 OMSG had 35 member physicians and accounted for 25 to 30% of primary care visits for Rochester residents. OCH had 45 physicians with staff privileges and advertised itself to the community with the telling slogan "The Personal Touch...Is What Makes Us Different.")

Mayo designated a section of Internal Medicine about 30 years ago to expedite the care of local residents, and more recently began a Division of Community Medicine and a Section of Family Medicine. In order to become more attractive to local residents, Mayo built the Baldwin Building for Community Medicine in 1979. Baldwin allows local patients to get the bulk of their medical tests and consults done under one roof with little waiting.

Mayo and OMSG together account for almost all the health needs of local residents. A 1974 household survey sponsored by all local health facilities showed that 90% of Olmsted County residents usually went to local Rochester health facilities for minor medical care, and 96% went to local health facilities for major medical care (Olmsted County Survey 1974:18,24). Mayo Clinic epidemiologists estimate that in one year 80% of the community is seen at the Clinic or some other local health resource, and in three years 95% (Kurland and Molgaard 1981).

This ability and preference of local residents to get all their medical care locally has allowed the Department of Medical Statistics and Epidemiology at Mayo Clinic to conduct a broad series of population-based studies of disease. The next section describes the development of the administrative procedures and database that have made these studies possible.

The origin of epidemiologic studies at Mayo Clinic

Rochester's contemporary importance as the site of many epidemiologic studies derives from a series of internal Mayo Clinic procedures adopted for administrative purposes at the beginning of this century. Until 1907 each physician within the Mayo family's medical practice kept his patient's records in his own set of leather-bound ledgers (Kurland and Molgaard 1981:54). To follow the course of an individual's illness it was sometimes necessary to consult the many ledgers kept by the various physicians who had seen a patient, the surgeons who had operated, and the laboratory. In 1907 Henry Plummer, a physician who had joined the Mayos' practice in 1901, instituted what he called the 'unit-record system', to enter in one place information that previously had been distributed among many different Mayo files. He also designed two indexing systems to keep track of the diagnoses and surgical procedures made by the 12 physicians then practicing in the group. This facilitated the publication of studies based on case lists of particular diseases, studies which emerged with increasing frequency from the Mayo practice. In 1931 Plummer authored the first population-based investigation of disease rates done at Mayo Clinic, a study of goiter among Olmsted County residents.

The diagnostic indexing system was expanded in 1935 by Joseph Berkson of the Clinic's department of physiology, and converted to punch cards that could be read, tabulated, and sorted by machine (Kurland and Molgaard 1981:56-7). Berkson included a code indicating residence within the city of Rochester, which allowed subsequent studies of disease to include only Rochester residents. In 1974 the diagnostic index was revised again, this time combining a four digit system based on the International Classification of Diseases with more specialized classifications developed at the clinic.

A patient's record at Mayo now consists of a single file containing a patient's biography and clinical history, laboratory and pathology reports, test results, primary and consulting physicians' notes, hospital charts, nursing and social service notes, and correspondence. No physician-patient encounter is supposed to occur without some diagnosis being entered on a record face sheet; these diagnoses then are coded and entered into a computer file by trained clerks. Most records are stored in a climate-controlled area in one building; staff can order them using a patient's seven digit clinic number and receive them within a matter of hours. The staff of the medical records section take great satisfaction in the fact that less than 300 records are lost among the 3.8 million in storage in 1985.

For the first half of this century almost all local residents sought medical care from Mayo, and thereby came to be listed in its diagnostic index. Since the Clinic's facilities were used by such a high proportion of Rochester residents, it was possible to use the diagnostic index as an inexpensive and effective substitute for finding cases of illness through household surveys. Mayo's historically dominant market position thus contributed to its strength as an epidemiologic resource. Though other independent private physicians not affiliated with Mayo have always practiced in or near Rochester, for many years Mayo was the only resource offering hospitalization or complex laboratory analyses. This caused patients under the care of non-Mayo physicians to be listed in the Mayo diagnostic index if their illnesses were severe or their diagnoses complex.

With the advent in 1955 of the Olmsted Medical Group (now called the Olmsted Medical and Surgical Group, OMSG), and the construction of Olmsted Community Hospital (OCH) that same year, Mayo was no longer the only source of hospitalization for all diseases, though OMSG physicians still commonly sent their patients to Mayo for complex lab tests. Funds obtained in 1966 from the National Institute of General Medical Sciences for a "Rochester Epidemiology Program Project" allowed the diagnostic index to be expanded to include patients seen at OCH, OMSG, two solo general practitioners, and other nearby health facilities. A version of the Mayo diagnostic index has been used since 1966 at the Olmsted Medical and Surgical Group and the Olmsted Community Hospital; the Project employs a diagnostic coder at OMSG whose duties are the same as those of the coders at the Clinic, and sends its abstractors out to look at patient records in health services in surrounding counties. The Project has also allowed diagnostic indexing to begin for the records of Rochester residents at the University of Minnesota Hospitals and the Veterans Administration Hospital in Minneapolis, and at clinics and hospitals in counties adjoining Olmsted.

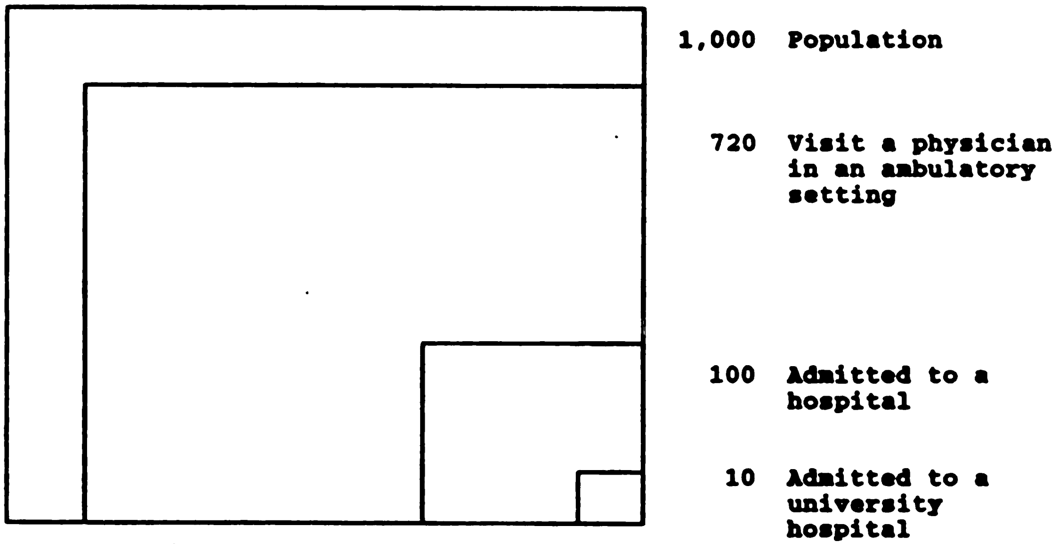
The diagnostic index and files of the Rochester Epidemiology Program Project have become a unique resource of international importance. More than 80 visiting scientists, research associates, medical and doctoral students, and more than 150 Mayo Clinic staff clinicians and residents initiated research within the Rochester Project from 1980 through 1985. Studies have concentrated on the epidemiology of cancer, cardiovascular and cerebrovascular disease incidence and risk factors, connective tissue, neurological, metababolic and endocrine disorders. More than 350 publications have resulted from the Rochester Project since its inception in 1966.

To underscore the importance of community-based studies of illness, the two following figures graphically display the potential biases inherent in generalizing from hospital and clinic-based studies to the community at large. Figure 2.1 is a diagram from Kerr White (1974), estimating the proportion of the total U.S. population that is seen annually by physicians in ambulatory care settings, hospitals, and university-based hospitals. White's point here (and in an earlier paper [1961], entitled "The ecology of medical care") is that many factors intervene between the first sign of symptoms and a referral to a medical center, hence studies based only on patients seen in the university hospital usually cannot give valid information for the health problems of the community as a whole. White warns of the dangers of using medical--and especially hospital--consults to generalize about individual's symptoms and health needs.

FIGURE 2.1

PERSONS USING THREE LEVELS OF HEALTH SERVICES IN THE U.S.A.

ANNUAL RATES PER 1,000 POPULATION, 1970

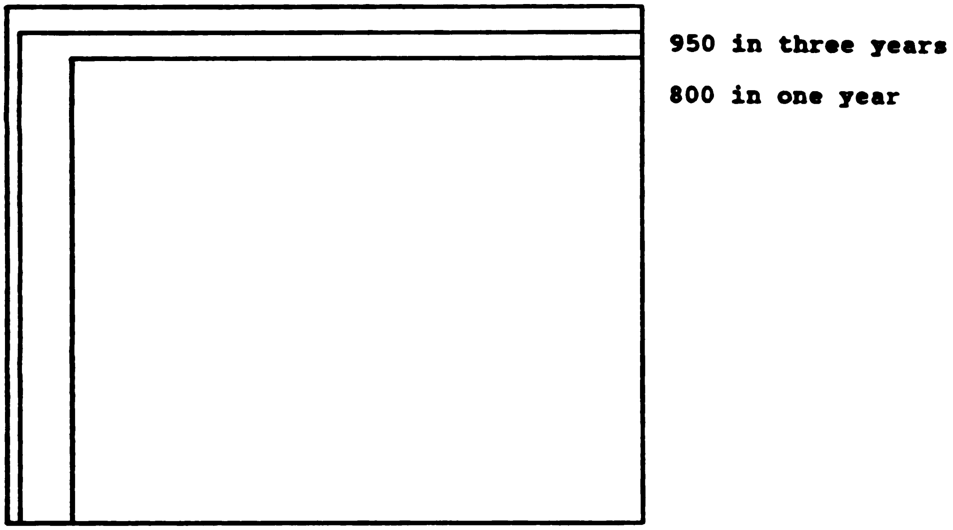


(FROM WHITE, 1974)

FIGURE 2.2

PERSONS USING HEALTH SERVICES IN ROCHESTER, MN

PROPORTION OF LOCAL POPULATION SEEN WITHIN ONE AND THREE YEARS



(FROM OLMSTED COUNTY SURVEY 1974)

Figure 2.2 uses a similar structure to display the "ecology of medical care" in Rochester: since large proportions of Rochester residents are seen over time in local health facilities, the medical records included in the Rochester Epidemiology Program Project describe the medical encounters of the populace. White's lesson about symptoms recognized but not brought to medical attention applies even to the Rochester case, but when the illnesses being studied are quite likely to involve medical consultations at some point, then a medical record-based study with complete population coverage can substitute for a community-based survey. This issue will be discussed more completely in the following section about the Rochester epilepsy studies.

Epidemiologists refer to these concerns as "selection biases," which are defined as "errors due to systematic differences in characteristics between those who are selected for study and those who are not" (Dictionary of Epidemiology 1983:12). "Berkson's bias" (named for Joseph Berkson, a former head of the Medical Statistics and Epidemiology Department at Mayo) is one type of selection bias that happens when a disease and its cause both increase risk of hospitalization. Mayo researchers have long had been interested and engaged in studies of selection biases. Their studies, and the methods of epidemiologists more generally, provide important resources for anthropologists and other social scientists concerned about whether their findings can be generalized to other groups.

Methods used in epidemiological studies of epilepsy in Rochester

The research described here sampled from a list of cases of epilepsy that had been collected from the medical records of Rochester residents over the past 30 years. To understand the general procedures of the Rochester Epidemiology Program Project, and to see the scope and limitations of the epidemiologic database for epilepsy that formed the sampling frame for this particular study, it is important to explain in greater detail how and why the database was developed.

Studies of the epidemiology of epilepsy in Rochester began in the late 1950s, when Dr. Leonard Kurland, a neurologist and epidemiologist, used the Mayo diagnostic index to search for cases of convulsive disorders among Rochester residents between 1945 and 1954, inclusive. At that time local physicians not affiliated with Mayo were still referring patients with recurrent seizures to Mayo, since Mayo had the only neurologists and electroencephalographs available to evaluate these cases.

All Rochester Project studies use diagnostic rules to decide who should be included and who excluded as a case: Kurland defined epilepsy as consisting of a history of more than one seizure. Acceptable causes of seizures included factors such as prior alcohol consumption or encephalopathy. Cases were rejected if seizures were judged to be "fainting attacks," or associated with hysteria, cardiovascular syndromes, or recognized metabolic disturbances such as uremia or hypoglycemia (Kurland 1959:145). Patients with seizures associated with febrile illnesses were included but categorized separately. People whose symptoms never were disruptive enough to cause them to seek medical care were not included in the database since they never would have received a diagnosis of epilepsy, but this total is likely to be small and possibly invisible even to community-based interviewers.

The 1959 study of epilepsy was updated and expanded in the early 1970s to include the period 1935 to 1967 (Hauser and Kurland 1975). (Comprehensive updates can rarely be done for any period ending more recently than two years prior to the time of the study, because it takes time for diagnoses to be entered into the index and recalled, and for records to be selected, reviewed, and abstracted.) Indexes from Mayo, OMSG, OCH, and adjacent services were brought together in a central file for all those diagnoses potentially indicating epilepsy. These included diagnoses describing a variety of types of seizures and epilepsies. If death certificates mentioned epilepsy then corresponding records were reviewed. Diagnoses sometimes associated with epilepsy were also examined: people who had had eclampsia, encephalopathy, cerebral palsy, brain tumors, and cerebrovascular accidents had their medical records collected and reviewed, and if they were identified as cases of epilepsy their records were abstracted. Cases were excluded if episodes such as loss of consciousness could have had cardiac or vasomotor causes, or if they were judged hysterical or caused by breath-holding or hyperventilation (Hauser and Kurland 1975:13).

Rochester residents were included as incidence cases only if the onset of their seizures followed their residency by at least one year. (This was to exclude people who moved to Rochester specifically to receive care for their epilepsy.) This one-year rule was applied to all residents, including students at the local community college, families of Clinic Fellows, and the Sisters of St. Francis (a local convent). Patients institutionalized at Rochester State Hospital, a state psychiatric hospital closed in the 1980s, were counted only if they were residents of Rochester or Olmsted County before they were institutionalized. College students with epilepsy studying away from home were included as cases if they maintained Rochester as their residence, but people serving in the military were excluded; the 1-year residency requirement was waived for returned servicemen who could have been considered residents when they were inducted into military service (Hauser and Kurland 1975:12).

The 1935 to 1967 update produced more than 2,900 records with suggestive diagnoses; approximately 10% of these were identified from non-Mayo sources. Following clinical review of the 2900 records, 1448 met the established residency and seizure requirements (Hauser and Kurland 1975:16). About half, or 708 of these were considered to have epilepsy, defined as recurrent seizures. The others were grouped into cases who had had a single seizure of undetermined cause, had one or more seizures related to acute metabolic disturbances or structural brain lesions, or had one or more seizures associated only with febrile illness. These last three groups do not meet the diagnostic criteria for epilepsy, and will not be considered further here.

The 708 persons who had had recurrent seizures were identified almost entirely from Mayo records; only 2% were found from records of OMSG, OCH, or the State Hospital. This reflects Olmsted County's continued reliance on the neurologic and electroencephalographic resources of the Mayo Clinic during the study period. (OMSG physicians still send their patients to Mayo for electroencephalography, and began to do some of their own lab work for anticonvulsant monitoring in 1984.)

Hauser and Kurland's 1975 study was designed partly to evaluate the long-term prognosis of epilepsy. (Their results were cited in Chapter One.) In order to get complete information for their study, follow-up of cases was crucial. Letters were mailed to verify addresses, and calls or visits were made when information on seizures, medications, or complications was not covered adequately in the medical record. Death certificates were reviewed and next of kin interviewed where possible to obtain details about cause of death or history of convulsive episodes. Similar procedures were followed in an update of the incidence and prevalence cases of epilepsy as of 1980.

In sum, the 1980 database contains information on both incidence and prevalence cohorts of people with diagnosed epilepsy who were Rochester residents between 1935 and 1980. Given the early development and unique history of the Clinic record system, this is the most complete and best documented series of cases in any population-based study of epilepsy.

Using the Rochester database for a psychosocial study of epilepsy

The richness of the Mayo diagnostic index as an epidemiologic resource has meant that it has been used for hundreds of epidemiologic studies. Careful procedures have been established to help balance the needs of the Mayo Clinic and the right to privacy of the institution's clients with the needs of staff and visiting researchers who use the index. The Mayo Clinic limits access to its records to Clinic staff--outside researchers must collaborate with Mayo investigators in any proposed research, and must obtain Clinic affiliations and approvals before they can examine any records. No information can be published or released to individuals outside Mayo Foundation if that information might be used to identify the participants in any particular study. Only statistical studies are given access to the diagnostic index; researchers interested in case reports or other methods that would identify individuals are discouraged from doing such projects at Mayo.

The process of obtaining Clinic approvals is complex, well-codified, and rigorous: the manual of procedures and guidelines published by the Mayo Institutional Review Board is more than 85 pages long. Investigators from outside Mayo must interest Mayo staff in their projects, obtain letters of support, and pass through a number of separate review committees before finally submitting their project protocols to the Mayo Institutional Review Board. Methods must be described in detail, as well as human subjects protocols, proposed informed consent and medical record abstract forms, any other data gathering forms, and proposed patient contact letters.

Submitting and revising these various forms and obtaining approvals from the required committees took approximately nine months for this project, since it departed somewhat from the procedures and research topics familiar to the Mayo reviewers. The diagnostic index had rarely been used to find community cases for interviews, and never for interviews about social issues such as medication and health service use, legislative sanctions, or social stigma. Protocols using the more familiar medical record abstracting methods have gone through the review process considerably more quickly. The project was separately reviewed by the following committees: the Department of Medical Statistics and Epidemiology Research Review Committee; the Multidisciplinary Statistics and Epidemiology Review Subcommittee of the Mayo Research Committee, the Neurology Research Committee, the Neurology Epilepsy Committee, the Mayo Institutional Review Board, and the Medical Relations and Publications Committee. I obtained the required Mayo affiliation by virtue of my title as Visiting Predoctoral Student within the Department of Medical Statistics and Epidemiology; this was approved by the Admissions and Student Progress Subcommittee and the Research Training and Degree Programs Committee. Research protocols were also submitted to and approved by the Human and Environmental Protection Committee of the University of California at San Francisco.

Design and use of interview and record abstract forms

The time spent shepherding the protocol through the various committees at Mayo was prolonged but ultimately helpful--the project was reviewed more rigorously during this process than it had been during earlier funding reviews, and the intervening months gave me time to create, test, and revise the proposed interview form. Earlier dissertations on epilepsy (Droge 1983, Ferguson 1982, March 1984, Shope 1978) provided helpful ideas about content and wording of questions about psychosocial issues, and work by the Social Science Research Council (Sudman and Bradburn 1982:174-205) provided standard questions to assess demographic variables. An early draft of the interview was discussed and tested among members of a San Francisco Bay Area epilepsy group.

The Mayo Institutional Review Board approved the project in June, 1985, and I moved to Rochester and started work there late in August.

Though the interview and record abstract forms were complete, each had been designed without detailed knowledge of the local Rochester community or the contents and variability in the medical records. To adapt both forms for use in Minnesota I contacted a statewide epilepsy consumer group, the Epilepsy Foundation of Minnesota (E.F.M.), and arranged to discuss and test the questions with E.F.M. staff and members in Minneapolis/St. Paul (90 miles northwest of Rochester) and St. Cloud (a town 150 miles northwest of Rochester that E.F.M. staff thought demographically similar to Rochester). E.F.M. staff were involved in campaigns to reduce the State's driving restrictions for Minnesota residents with epilepsy, and to make health insurance more available and affordable to this group. They welcomed the opportunity to get community-based information about these issues, since their own membership surveys could only assess the experiences and views of people who had already sought their assistance. These meetings resulted in new interview questions about driving, insurance coverage, and means of payment for medical care.

E.F.M. members in the Twin Cities were consulted about the issues they thought were most important to examine among people with epilepsy, and the best wordings for questions. This led me to include a new item about whether interviewees had ever had seizures that they had not told anyone about. E.F.M. members in St. Cloud were interviewed and then debriefed in detail about the interview process. In addition to giving me practice in interviewing, this made it possible to clear up remaining ambiguities in the wording of particular questions, and to check the sequence and flow of topics within the interview. The final interview form was completed by the end of October (see Appendix 4). Before the interview was ever used among Rochester residents it had been tested and revised six times.

I adopted a similar pretesting strategy to make the record abstract form (Appendix 3) accurate and easy to use. I first selected a random sample of 20% of the 200 medical records from among Rochester residents aged 18 to 59 listed in the epilepsy index of the Rochester Project. These records showed where the various medical information was noted, what sort of variability there was in the comprehensiveness or legibility of physician's notes, and whether the proposed information on medication use would in fact be available in a high proportion of records. Following this review, the revisions of the abstract form which it prompted, and another practice session, all records were abstracted again beginning in mid-October.

Two part-time assistants were hired to help with abstracting and interviewing, thereby increasing the speed and reliability of the research. Both were nurses who had already been trained for work in the Department of Medical Statistics and Epidemiology. I had written an abstracting protocol to accompany the record abstract form; this was reviewed with Joan LaPlante, the abstractor, who then practiced on a series of charts until her findings agreed with my own. Later in the study two records were inadvertently abstracted by both of us; our findings on these two abstract forms were identical. Joan abstracted 55% of the records and I the remainder.

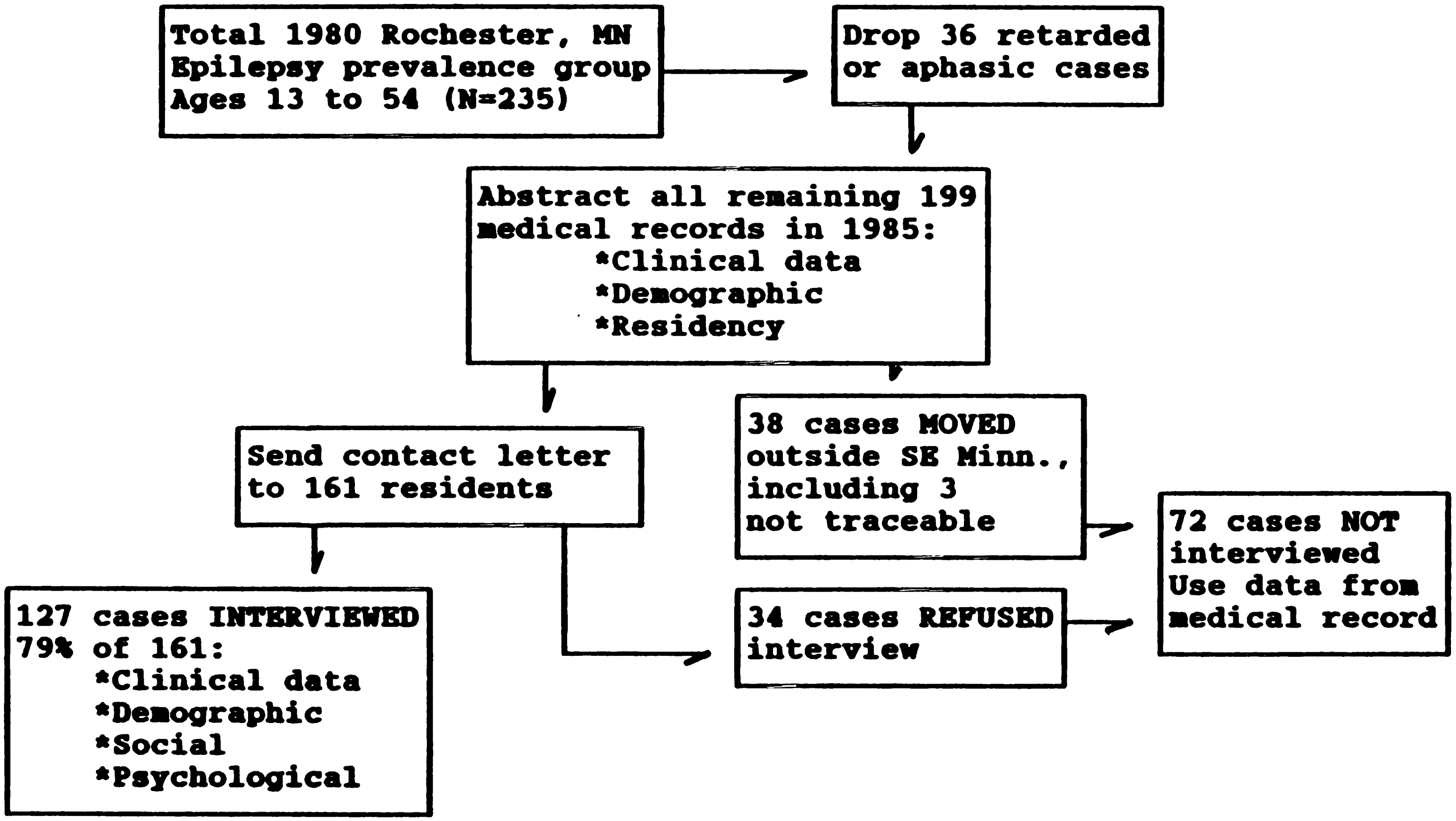
Joanne Ward, the part-time interviewer, had been trained during an earlier community survey of health service utilization sponsored by the Department of Medical Statistics. We worked together to familiarize ourselves with the interview form, interviewing friends, family, and one another, and discussing the results. In November we did the first few interviews together, one interviewing and the other observing. After the first 25% of the interviews were completed we began to code them. Each worked on the other's interviews; together we discussed questionable interpretations until we resolved them. The resulting codes formed a skeletal coding dictionary used for the remaining interviews, when each of us coded our own. Joanne Ward completed 53% of the interviews and I the rest.

Non-response problems

Finding potential study participants, the most difficult and expensive part of many studies, was in this case the easiest. Since the clinic numbers of Rochester residents with seizures had already been collected in a computer file, our sample was drawn simply by specifying the desired age range (13 through 54 on January 1, 1980) and clinical status (prevalence cases of epilepsy as of January 1, 1980, I.Q. above 75, no other medical conditions present that would make interviewing impossible). Within three days a list of 203 appropriate clinic record numbers was delivered, which enabled us to request patient medical records for review. During the review of these records four of the cases were dropped from the study. Two did not fit the criteria as prevalence cases for 1980, one was retarded but had been miscoded, and one had died after 1980. The following flowchart (Figure 2.3) shows the study's design: 235 cases were identified in the age range, 36 were dropped, and among the remaining cases 38 had moved or were not traceable. Of the 161 people residing in Rochester, 79% were interviewed.

FIGURE 2.3

STUDY DESIGN



After we received medical records from storage, we entered names and addresses on the abstract forms along with the relevant data on date of last seizure, date of last medications, number of anticonvulsant levels, whether there were notations describing incidents of noncompliance, occupation, and date of last residence in Rochester.

Interviewing began once we had abstracted a critical number of records. We were unable to reach and schedule efficiently more than 60 cases at a time, so we divided the potential interviewees into three waves of mailings. Invitation letters (see Appendix 1) to the first batch were mailed in mid-November, but this batch had a far higher non-response and refusal rate than anyone had anticipated. The customary followup letters and short clinical questionnaires used by the Department of Medical Statistics usually had better than 95% response rates. However, in this study only about half (28) of 49 people residing in the area sent back a postage paid reply form, and about 40% of these refused any further contact with the project. The first contact letter mentioned that those who did not return the reply form would be called; three of these also refused to participate. The refusal rate in the first batch was 29% of those who were traceable and had not moved from the area (14 of 49). (The first wave included 67 cases: 16 had moved out of the area, and two could not be traced.)

The high proportion of refusals from the first batch of contact letters caused us to rethink our approach. Mayo protocol did not allow us to contact these people further, so we had no way to assess why they refused. Possible reasons for their reluctance include the season (the proximity of Thanksgiving, Christmas, and New Years), shame or perceived stigma about epilepsy, frustration based on receiving many earlier study invitations from Mayo, or an insufficiently attractive invitation letter for this study. Since we could only influence the first and last possibilities, we redrafted the letter of invitation, submitted it again to the two necessary committees, and waited until after the beginning of the New Year to send out the revised version (see Appendix 2). Whether it was season or letter wording we cannot know, but refusal rates dropped from 29% in the first wave to 20% in the second and 14% in the third. A final possibility that may have influenced the refusal rate was that the first batch contained a higher proportion of people who had not been seen recently in the clinic and who had had over the past five years fewer tests related to their seizures (Table 2.5). If these people were least likely to be in contact with the clinic they may also have been least likely to participate in clinic research studies.

Table 2.5
Clinical differences between interview batches

Variable	Batch 1	Batch 2	Batch 3	F test
(Mean years elapsed since most recent seizure-related test)	3.7	3.0	2.8	n.s.
(Mean # of seizure-related test appointments in five years)	5.5	6.0	6.3	n.s.
(Mean years elapsed since most recent clinic visit)	2.4	1.9	2.4	n.s.
(Mean years elapsed since last seizure)	6.6	5.8	6.6	n.s.

The refusal rate overall was 21% among people resident in the area and potentially available for interview (Figure 2.3). Follow-up of potential interviewees was nearly perfect, with only three of 199 not traced. However, with more than a third of the original prevalence group not interviewed because either they refused to participate (34 people) or no longer resided in the area (38), it is important to assess whether there are any important and systematic differences visible between those who were interviewed and those who were not. If such differences exist then one cannot generalize the responses of interviewees to the group as a whole. This is the advantage of having a complete population census of records, since demographic and clinical data is available even for people who emigrate or refuse to be interviewed.

Table 2.6 shows that those who moved were more likely to be young, male, and in managerial and professional occupations; those who refused were more likely to be older and in production and operator occupations. While the demographic picture of those interviewed is not significantly different from those not interviewed, this is because demographic differences between emigrants and refusers cancel each other out--emigrants were younger and male, while refusers were older and female. ANOVA tests of age stratified by interview status and sex show significant differences between the groups, ($F=3.08$, $df=2$, $p<.055$), with post-hoc tests showing that emigrants are younger than interviewees and refusers (mean age of 35 for emigrants, 39 for interviewees, and 40 for refusers). While statistically significant, this difference is not large enough to be methodologically significant.

Table 2.6
Demographic comparisons
among cases from 1980 Rochester prevalence list:
Totals, interviewees (in 1985), refused, and moved.

VARIABLE	TOTAL (N=199)	INTERVIEWED (N=127)	REFUSED (N=34)	MOVED (N=38)
Age in 1985	%	%	%	%
18-29	29	25	29	42
30-39	27	29	15	29
40-49	28	29	32	21
50-59	16	17	24	8
Sex				
Female	58	62	56	45
Male	42	38	44	55
Occupation in 1980	(N=148[1])	(N=98)	(N=24)	(N=26)
Management	22	22	19	29
Clerical	35	36	33	29
Service	17	18	13	12
Farm	2	2	0	4
Production	9	7	15	8
Operators & Laborers	14	13	15	17

[1] (Excludes housewives and students, includes the unemployed.)

Comparisons of clinical records of interviewees, refusers, and emigrants give similar results: Table 2.7 shows that the three groups did not significantly differ according to number of epilepsy-related appointments, number of noncompliance notations, nor years since last medication, last neurology visit, first seizure, first medication, or epilepsy diagnosis. Those who had moved away from Rochester had had more time elapse since their most recent visit, but this was not statistically significant. The only significant clinical difference among the groups is in time since last seizure, which is shorter for the emigrant group since it has fewer years of followup. Overall there appear to be no significant demographic or clinical differences among the groups to prevent generalizing from interviewees to the whole group.

Table 2.7
Chart-based
Clinical comparisons among Rochester cases:
cases interviewed, refused, and moved

	INTERVIEWED (n=127)	REFUSED (n=34)	MOVED (n=38)	
VARIABLE	MEAN	MEAN	MEAN	ANOVA SIGNIFICANCE
Age	38.9	39.9	34.5*	<.05
Years since last seizure	6.3	8.4	4.3*	<.04
Years since last neurology visit	2.8	3.3	4.5*	<.02
Years since last visit	2.1	2.6	2.3	N.S.
Years since first seizure	22	23	19	N.S.
Years since epilepsy diagnosed	19.1	20.2	17.1	N.S.
Years since medication first prescribed	16.2	16.7	14.0	N.S.
Number of epilepsy tests within 5 years of last follow-up	5.8	5.8	6.4	N.S.
Number of noncompliance notes since 1975	2.2	1.4	2.2	N.S.

(*=significantly different from other groups at $p < .05$ by Newman-Keuls post-hoc test)

Incidence compared with prevalence cases

Another factor which might bias the results of this study derives from the way in which cases were selected: the cases analyzed here are cases *prevalent* in Rochester as of January 1, 1980. Prevalence cases are the number of cases of a particular disease in a defined population at a defined instant in time, while incidence cases are the number of new cases of a disease that occur within a defined population at risk over a specified period of time. Incidence of disease can be compared among different populations when measured with a rate, the proportion of new cases among all cases at risk multiplied by some constant. Incidence rates estimate the probability of developing a disease during a defined period of time, and are most representative of the causes of disease. Prevalence rates estimate the burden of disease in a defined population, and are thus not as reliable an indication of disease risk as incidence rates are.

Prevalence rates result from many separate dynamic processes. A prevalence rate is sometimes described as a snapshot of a changing process that includes incidence rates, duration of illness, migration, medical care, and mortality. Numerators increase as new cases occur among residents, or cases diagnosed elsewhere move into the community; at the same time numerators decrease as cases die, stop having seizures and become "inactive," or move away.

Since the Rochester studies rely on medical record abstracting, complete and comparable clinical information is available only for people who resided in Rochester at the time their epilepsy was diagnosed and the clinical record of their condition began. For example, the 1980 prevalence study abstracted the date of first medication and date of first seizure only among incidence cases, since researchers felt there would be too much uncertainty and non-random error if they were to try to obtain these dates for people whose seizures or treatment began before they moved into Rochester. It might be argued that this should cause researchers to study only incident cases in Rochester: these have the most complete and accurate clinic records, and for the reasons stated above they provide more accurate data about risk factors for acquiring epilepsy. I reasoned however that I was more concerned about epilepsy management than risk factors; describing a series of prevalence cases would describe a diagnosed segment of the Rochester community, and would give information more useful to service providers.

The Rochester records allow studies to distinguish between Rochester prevalence cases that are also Rochester incident cases, and Rochester prevalence cases that have been diagnosed elsewhere and subsequently moved into Rochester. The distinction between incident cases and prevalent cases is important since so many unknown factors may have led diagnosed cases to become residents of Rochester: perhaps these people moved into Rochester to obtain better care than they had received in their former communities, or perhaps they thought they would encounter lower levels of social stigma in a medically-centered community. If these kinds of reasons governed their migration into Rochester then incident and non-incident cases might differ in systematic ways (for example, severity of the seizures or extent of control), leading to biased results. We examined this using the variables available in the 1985 abstract data, which did not measure perceptions about quality of medical care or social stigma in Rochester, but did include extensive demographic data.

Other studies of chronic illness in Rochester have found certain demographic and clinical differences between incident and prevalent cases: for example, an epidemiologic study of Rochester residents with diabetes found a disproportionate number of elderly females among prevalent cases compared with incident cases (Melton et al. 1983). The researchers suggested that the prevalent group was comprised largely of elderly widows, who moved from outlying farms into Rochester nursing homes and apartment houses when their health became impaired (Melton et al. 1983:430, Melton: personal communication). The age range (18 to 59) established for my study should preclude this particular effect if indeed it also occurs among people with epilepsy; nonetheless I compared the 103 incident cases and 96 prevalence cases for age, sex, occupation, employment, and interview status to see whether there were any significant differences. Table 2.8 shows that the distribution of incident cases compared to prevalent cases is somewhat skewed toward the younger ages, though the sex ratio is quite close.

TABLE 2.8
Age group, Sex, and Occupation
as Percentage of Incident and Non-incident groups

		Incident	Non-Incident	
AGE	18-29	36%	22%	X^2 (3 df)= 5.51 ($p<0.14$)
	30-39	22	31	
	40-49	25	31	
	50-59	17	16	
TOTAL (n)		(103)	(96)	

		Incident	Non-Incident	
SEX	Male	41%	44%	X^2 (1 df)= 0.07 ($p<0.78$)
	Female	60	56	
TOTAL (n)		(103)	(96)	

Table 2.9 shows the occupational and employment distribution of the incident and non-incident groups: incident cases are better represented in the technical/clerk and farm/production occupations, and prevalent cases in the service and operator/laborer occupations. Employment status is much the same for each group. None of these differences in

distributions are statistically significant by Chi-square measures of association. The final category examined was that of interview status: prevalent cases appeared twice as likely to have moved away from Rochester as incident cases, and were therefore less likely to have been interviewed ($p<.051$). The higher rate of out-migration among prevalent cases in all likelihood is due to their employment: having moved in after their seizures began, they are somewhat older, and form part of the more recent and more mobile Rochester workforce.

TABLE 2.9
Occupation, employment, and response status
as percentages of incident and non-incident case groups

<u>OCCUPATION</u>	Incident	Non-Incident	
Management & Profession	21%	25%	
Technical & Clerical	41	29	
Service	12	22	X^2 (4 df)=7.42 ($p<0.12$)
Farm & Production	15	7	
Operators & Laborers	11	18	
TOTAL (n)	(75)	(73)	

EMPLOYMENT <u>STATUS</u>	Incident	Non-Incident
Unemployed	4%	6%
Employed	71	71
Student	10	6
Housewife	13	15
Disabled	2	2
TOTAL (n)	(100)	(95)

RESPONSE <u>STATUS</u>	Incident	Non-incident	
Interviewed	68%	59%	
Refused	19	15	X^2 (2 df)=5.9 ($p<.051$)
Moved	13	26	
TOTAL (n)	(103)	(96)	

In sum, Tables 2.6 and 2.7 show that interviewees do not differ significantly from residents of Rochester who refused to participate, but that these two groups both differ from those who moved away. This is a problem inherent in using a 1980 source to find and interview people 5 years later. To be a truly representative picture of Rochester residents in 1985, two groups would need to be included in the study: those people with diagnoses of epilepsy who moved in to Rochester between 1980 and 1985, and those people who first developed epilepsy between 1980 and 1985. Tables 2.8 and 2.9 show that there is more out-migration among prevalent cases than among incident cases. The exclusion of new incident cases from the study may make adjustment to epilepsy appear easier for the group as a whole, while the loss of emigrant cases and the inability to include new immigrants may effect the figures on occupation and employment. These are appropriate subjects for future research in Rochester, and they qualify the results given here.

Topics covered in medical record abstracts

Chapter One described the overall objectives and rationale for this study. This section, and the one following, describe the specific variables and measurements used to complete the study's objectives.

Some clinical and demographic data had already been abstracted for the cases on the 1980 prevalence list, and therefore did not need to be abstracted again. These included clinic number, other medical record number if any, birthdate, sex, marital status at diagnosis, predisposing cause, seizure classification, presence of mental retardation or cerebral palsy, residence on prevalence day, and medications prescribed on prevalence day (see Table 2.10 for a listing of abstracted variables, and Appendix 3 for the abstract form.) The following dates had also been abstracted for all cases: last Rochester residency, last follow-up, first seizure, and first epilepsy diagnosis. The following dates had been abstracted only for incidence cases, that is, cases who developed epilepsy when they resided in Rochester: last seizure, first medication, last medication, remission with and without medications, and relapse.

TABLE 2.10
Variables Abstracted from Medical Records

DEMOGRAPHIC
Birthdate
Last SE Minnesota residency
Sex
Marital status at diagnosis
Residency on prevalence date
Occupation in January 1980
Mayo record number
Other medical record number
Last follow-up status

CLINICAL
Date of: first seizure
- first epilepsy diagnosis
- last seizure
- first medications
- last medications
- remission without seizures
- remission without medications
- relapse
- remission after relapse

Raw MMPI scores and date tested
Seizure classification
Predisposing cause
Mental retardation or cerebral palsy

TREATMENT
Prescribed medications
Number of noncompliance notations in record since 1/1/75
Text, date, author, and location of notes
Most recent anticonvulsant plasma level
Date of level
Dose of anticonvulsant
Weight on above date

SERVICE USE
Date of most recent neurology or seizure-related visit
Number of neurologic tests within 12 months and 5 years of above date (includes EEGs, plasma levels, CAT and other brain scans)
Number of missed neurologic appointments within 12 months and 5 years of above date

The 1985 abstract form designed for this study brought the categories of the 1980 abstraction up to date, and added the following information for all cases: occupation and employment status in 1980; clinical data such as date of last seizure, date of last medication, and date of last neurology or seizure-related visit; data about the regimen including number of neurology-related tests within 12 months and five years of the last visit, number of missed appointments within 12 months and five years of the last visit, number of noncompliance notes written in the medical record since January 1, 1975, date and text of each note, most recent plasma level of anticonvulsants listed in the record, along with medication type, date, and prescribed dose and weight on that date; and psychological data including raw scores on Minnesota Multiphasic Personality Inventory (MMPI) profiles if these were found in the medical record.

While we had intended to count office visits as well as neurology-related tests this turned out to be impossible. Some physicians entered phone conversations in the record as separate visits but others did not; some seizure-related visits took place as part of a general exam, others took place only in the neurology department. To avoid these problems we counted only those events which were likely to appear consistently in the record: electroencephalogram reports, blood level reports, and other miscellaneous diagnostic tests (CAT and other brain scans). These events served as rough measures of the intensity of a patient's epilepsy-related clinical encounters.

Topics covered in interviews

Only one contact with interviewees was administratively possible, so the interview covered a broad range of topics. Information was collected about demographic, clinical, attitudinal, psychological, and social variables. (Table 2.11 outlines the variables included under each category, and the interview form is included as Appendix 4). Some topics originated in the New York study discussed in Chapter One: use of health services and medications; beliefs about seizure etiology, precipitating cause, prognosis, and the efficacy of the therapeutic regimen; attitudes about disclosing epilepsy to others; and experiences with social or legislative sanctions such as problems with insurance or driving. These were the topics for which we wanted to obtain community-based estimates.

TABLE 2.11
Variables Measured at Interview

DEMOGRAPHIC

Age
Marital status
Education
Employment status
Occupation (present and usual)
Income
Household size
Social network

CLINICAL

Diagnosis
General health status
Chronic health conditions
Date of seizure onset
Date of epilepsy diagnosis
Recent seizure frequency
Cumulative number of seizures
Date of last seizure
Medication type(s) and dosage(s)
Date of last medications
Seizure-free periods (remissions)

ATTITUDES AND BELIEFS

Original cause of seizures
Precipitating cause of seizures
Prognosis
Efficacy of regimen
Disclosure
Locus of Control

SOCIAL SANCTIONS

Impact of seizures
Health, life, and car insurance
Driving

SELF-REGULATION OF TREATMENT

Missed appointments
Recent medication consumption
Experience of seizures while off meds.
Medication changed for 2+ weeks
Medications stopped for 3+ days
Reminders
Considered not seeing physician
Commitment to regimen

SERVICE USE

Source of general medical care
Source and satisfaction with care for seizures
Source and satisfaction with emotional support
Use of non-biomedical services
Self-treatment types
Source of payment
Medical expenses

Interviewing community-based cases about whom so much clinical information was known was a unique opportunity: the extensive data available in the medical records prompted me to try to assess the relative strengths and weaknesses of self-report and record-based information. This required asking interviewees about clinical topics such as the date of onset of their seizures, date of last seizure, medication type and dosage, and seizure type and frequency. These answers could be compared with information in the record to see how reliable the information reported in the interview was.

This, of course, assumes that the record is more reliable than a self-report during an interview. This conventional medical wisdom is almost certainly correct for incidents observed or initiated by medical staff such as diagnoses or seizures in the medical facility. It <u>may</u> also be correct for changes recommended by physicians, such as dates of medication changes, or prescribed dosages--depending on whether the patient in fact acts as the physician assumes. (This is discussed in more detail in Chapters Three and Four.) But much of a patient's history in a medical record is <u>also</u> based solely on patient self-report: date of diagnosis is best obtained from the entry of the examining physician, but date of first seizure often can be elicited only from the person who has had the seizure, or those who have observed it. Even when read from the record the absolute accuracy of the date thus ultimately depends on self-report. The advantage of the record is its immutability: even if the absolute accuracy of a date is in question, memories of that date can change through time, while the version in the record usually does not. For more recent events, such as seizures or dosage changes not yet (if ever) reported to one's physician, self-report will be the more accurate measure.

Additional interview topics came from other investigators' research on people with epilepsy. For example, one way to classify the beliefs of people with chronic illness is the Health Belief Model, developed by Becker, Kirscht, Maiman, Rosenstock, and colleagues at the University of Michigan, Ann Arbor (e.g., Becker 1974, Janz and Becker 1984). The Health Belief Model was first developed to predict acceptance of preventive health measures such as checkups and immunizations, and was subsequently modified to predict cooperation with treatment regimens for chronic illnesses. The model proposes that a person's cooperation with treatment depends on that person's perceptions of _susceptibility_ to the disease, its _severity_, the _expected_ _benefits_ of cooperating, and the perceived _barriers_ to acting. Later additions to the model included factors influencing a person's _readiness_ to cooperate with treatment (motivation to act, value of the action's outcome, probability that action will produce the desired outcome); and factors modifying or enabling action (demographic variables, structural constraints, prior experiences, physician/patient interactions).

Two dissertations studying the effects of Health Belief Model variables on cooperation with treatment regimens among people with epilepsy have given little support to the Health Belief Model. A study of pediatric epilepsy outpatients in Detroit, Michigan found partial support for two dimensions of the Model (Shope 1978). A study of adult epilepsy outpatients at 4 clinics in the Minneapolis/St. Paul metropolitan area found no support for variables based on the main Health Belief Model (Ferguson 1982). My study was designed partly to describe how people construct their own 'calculus of perceived risk of seizures'; it was then to use this calculus as a predictor of behavior related to medication consumption. This process will be described in more detail in Chapter Three, where I discuss medication consumption.

One of the existing controversies about the social effects of epilepsy is whether it leads to depressed income or occupation relative to educational attainment, that is, whether there is a 'downward drift' phenomenon (a tendency for people with epilepsy to advance more slowly, or to attain occupations with low pay or status despite adequate education and training) (Dominian et al. 1963). The only demographic variables available from the Mayo medical records were age, sex, occupation, employment status, and marital status, so more complete demographic information was obtained in the interview such as present employment status, present and usual occupation, years of schooling, degrees received, household size, income, and number dependent on income. These findings will be reviewed in Chapter 5, on the social and legislative sanctions faced by adults with epilepsy.

Summary

This chapter has described the importance of doing community-based studies of illnesses, and has reviewed the background, importance, and procedures for doing epidemiologic studies at Mayo Clinic. My project was an attempt to use the methods of descriptive epidemiology to study the social management of illness. Just as there is a natural history of disease, so there is also a natural history of disease management--a process that goes on inside and outside the walls of the medical clinic. Epidemiologic methods can help this natural history of disease management to be described more fully and clearly. The following chapter discusses theories and evidence about this process of disease management, using social theory to "unpack" the clinical notion of compliance with treatment.

CHAPTER THREE: THINKING ABOUT MANAGING MEDICATIONS

In this chapter I contrast professional and non-professional world-views about managing medication regimens. Physicians commonly study this under the topic of "compliance," defined in a leading bibliography as "the extent to which the patient's behavior (in terms of taking medications, following diets, or executing other lifestyle changes) coincides with medical or health advice" (Haynes 1979a:2). Contemporary interest in the topic of compliance can be contextualized within a broader network of concerns about consumerism and the future status of the medical profession. This chapter explores the meaning, clinical significance, and historical development of the concept of compliance. It raises a series of questions and critiques that are applicable to the study of compliance for people who have epilepsy as well as other chronic illnesses. The following chapter applies the ideas developed here to the management of therapeutic regimens by Rochester residents who have epilepsy.

I will argue in this chapter that compliance as a biomedical research topic would be improved by being distilled into component research topics; topics quite similar to other, already popular areas of social research about health and illness. Compliance research is largely centered in biomedicine, and frequently adopts the physician's perspective. But the way compliance research describes patient behavior overlaps with, and can be advanced by, sociomedical research topics such as self-care, use of alternative health services, illness behavior, the health-seeking process, and relationships between patients and healers. These research topics center on the patient's perspective and contribution to the healing process. They are a fertile source for information about the determinants and context of compliance.

The idea of compliance itself, and most research on the topic, is dominated by a series of ideological conceptions of the proper roles of patients and physicians: stated most baldly, much of the compliance literature assumes that physicians give orders rather than advice, and that patients should follow their orders. Enormous research energy has been devoted to searching for the patient-centered determinants (demographic, clinical, social, and psychological) of noncompliance with therapeutic regimens, but these efforts have produced few satisfying results. More has been explained using interaction-centered variables (quality of communication between patients and physicians, congruence of expectations, satisfaction, and the like), but even these variables used in multivariate statistical equations typically account for less than 20% of the variance in compliance.

Though presented as a literature about improving medical services, the research literature about compliance is preeminently a literature about power and control. It is written largely by medical professionals about themselves and their clientele; it reveals the medical profession's worldview in its formulation of the problem and prescriptions for change. Aside from providing glimpses of a profession's image of itself and its clients, the topics of compliance and noncompliance illustrate the development and functioning of social controls in the field of medicine. They also help to illuminate some of the fundamental issues in the therapeutic treatment of epilepsy, issues which frequently can be generalized to other chronic illnesses.

Why is medical compliance an important topic?

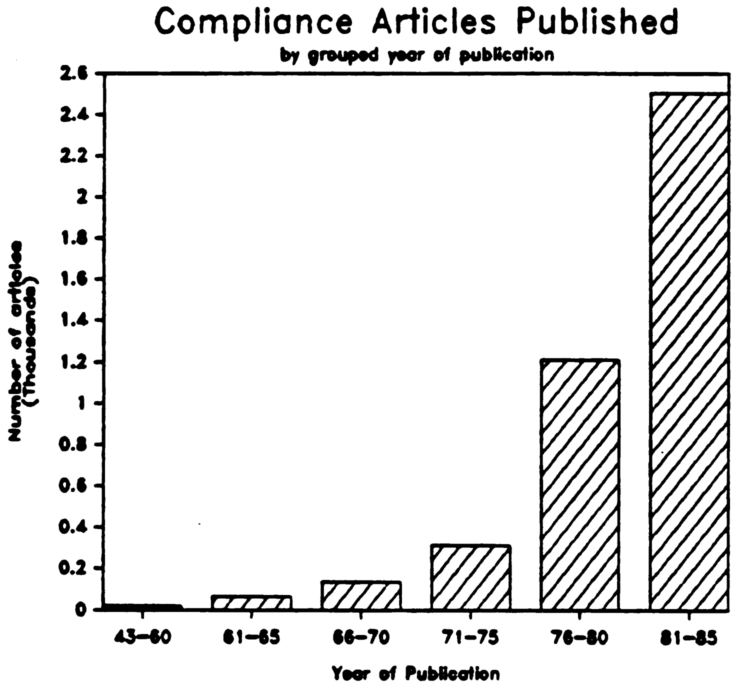
The significance of medical compliance can be assessed using economic, clinical, and academic measures. Many of the behaviors included within the above definition of compliance involve the use of pharmaceuticals or other health aids. These products constitute a sizeable portion of the United States economy: the total retail value of drugs and health aids sold in the United States in 1982 was 46.5 billion dollars, or 1.5% of the nation's gross national product, and the total retail value of pharmaceuticals sold in 1982 was over 16 billion dollars (U.S. Department of Commerce 1985). Compliance is frequently used by pharmaceutical companies within this large and competitive market as part of a promotional strategy to increase market share and product sales. The most basic rationale for this strategy is that compliance will increase medication consumption and increase sales. (For example, a national study of family health found that 10% of respondents often did not get first-time prescriptions filled, but rather waited to see if they needed them [General Mills 1979:155].) Increased compliance is one of a set of positive attributes advertisers use to increase a product's visibility. In addition, responsibly promoting proper dosage schedules increases a pharmaceutical company's positive public image, and reduces its economic and social liability should its products be abused. Practically any North American medical journal published since 1978 contains numerous advertisements proclaiming that a particular product's simple dosage or low level of side effects will increase patient compliance. These proclamations are frequently used to advertise treatments for chronic conditions such as arthritis, diabetes, epilepsy, and hypertension.

Compliance is more than an economic concern, for the irregular, diminished, or excessive consumption of medicine can cause clinically significant problems. Some medications, like penicillin, must be taken for a period well beyond the time at which symptoms disappear if they are to kill all the infectious organisms. Many drugs, especially the barbituates, are dangerous if taken in excess; others, e.g., aspirin, are not at all effective until a certain critical minimum level of medication is taken. Compliance can cause a medication's therapeutic effectiveness to be misinterpreted: a person's blood may show low levels of medication because not all the prescribed medication is being taken. If a physician then increases the dose, and the person subsequently takes the medication as prescribed, that person's consumption could then be dangerously high. A similar problem occurs on a larger scale in clinical trials of medications: high proportions of noncompliance can make a drug appear less effective than it really is (Feinstein 1979).

Studies estimate that about half of people who are chronically ill are noncompliant with their medication regimens (Sackett and Snow 1979). Chronic health conditions such as heart disease, hypertension, and diabetes are this country's major health problems, therefore noncompliance is by all estimates a common and important problem in the United States.

A final way to measure the importance of the topic of medical compliance is by the size and growth rate of the academic research literature: a cumulative bibliography on the subject (Haynes et al. 1979) listed only 22 articles in English published before 1960, and 850 published by 1978. More than 3200 articles in English were listed in the Index Medicus between 1979 and 1985, with more than 1100 appearing in 1984 and 1985. The following graph (Figure 3.1) shows the dramatic level of research interest in this aspect of patient-doctor relationships.

Figure 3.1



(Adapted from Haynes 1979, Figure 1.1,
and _Index Medicus_ postings.)

THE IDEOLOGY OF COMPLIANCE

The normative view of compliance

What does medical compliance mean today, and how has it come to have this meaning? The assumptions underlying the concept, the way it is defined in research studies, and the way it is used in clinical practice, all draw from theories about the proper relationship between physicians and their clients. I call compliance an "ideology" because it is based in these theories, yet has been used and studied as a real and valid category of human behavior. Ideologies differ from theories in that ideologies are shared beliefs that legitimize particular behavioral norms and values, at the same time that they claim and appear to be based in empirical truths. Theories are tentative propositions about relationships between concepts, or about aspects of the empirical world--they are less encompassing than ideologies, and make less effort to appear uniquely true. Ideologies help to transform power (potential influence) into authority (legitimate control). Compliance is an ideology in that it transforms physicians' theories about the proper behavior of patients into a series of research strategies and coercive techniques that appear appropriate.

In the few paragraphs that the major compliance bibliography devotes to history, an editor states facetiously that the "first recorded incident of human noncompliance in Judeo-Christian tradition" occurred when Eve ate the apple in the Garden of Eden (Haynes 1979a:3). But this bit of wit reveals some of the confusion inherent in the compliance literature: what manner of term is noncompliance if it can apply equally easily to a patient's nonconformity with medical advice, and to a Biblical figure's nonconformity with God's advice? Does God give advice or commandments? What about the physician? What sort of values does the term express if it can be applied in both these cases? While its author is joking, the biblical example is not serendipitous: Haynes co-edited the primary bibliography on the topic, and took some time within that work to state that his definition of compliance was intended to be nonjudgmental. Explicitly recognizing that the term "is troublesome to many people because it conjures up images of patient or client sin and serfdom" (1979a:2), Haynes stated that the editors of the volume knew of no acceptable alternative. One editor called the alternative words "technical jargon terms", thereby appearing predisposed not to look for substitute words rather than unable to find them.

Though compliance can be called a nonjudgmental concept, it rarely is used or studied in this way. Much compliance research manifests a series of particular attitudes, seen in the following egregious examples:

> Through instruction in health magazines, the Reader's Digest, and radio and television programmes, patients acquire that superficial knowledge which often emboldens them to question their doctor more closely than hitherto about their own complaints. Of course it is unlikely that a patient can have any real understanding about his illness, but the greater risk that he will obtain misguided information from less reliable sources has to be reckoned with. Greater profit, therefore, will be earned if the doctor affords time to talk to each patient with cardiac pain. (Evans 1959:252)

> Communication between doctor and patient ideally necessitates a certain degree of reciprocity. Each person has certain rights and obligations. When the doctor performs a service, the patient is obligated to reciprocate: first, by cooperating with the doctor in their interaction; and second, by complying with the medical recommendations once he leaves the doctor's office. (Davis 1968:284)

> Whether your patient needs to be reassured or warned, he needs to be made aware of his responsibility for taking medication as directed. Just as he decided to seek treatment, so he must decide to take his drug correctly and follow other particulars of his therapeutic regimen. Most patients appreciate the idea of being active partners in their treatment. (Weibert and Dee 1980:9)

> In some instances, the patient, because his condition is not improving or is getting worse (due to his failure to follow the prescribed regimen) may start a malpractice action. On a less critical level, the patient, and his or her family and friends may decide to go elsewhere for their health care. In addition, a discontented patient is not likely to help a physician's reputation in the community. That's why it's important for the physician to understand the motivations for the patient's noncompliance. (Van Camerik 1978:30, from an article entitled "Why don't patients do what you tell them?")

These four quotations contain a number of important assumptions found to varying extent in much of the literature about medical compliance. Evans portrays patients as ignorant and prone to act on misguided information. He urges the physician, as the proper source of authoritative information, to talk with patients NOT because it will help them understand their condition, but because it may make them less likely to consult other, supposedly less reliable sources. Patient education thereby becomes a strategy to prevent "improper" consults rather than to prevent illness. In the second quotation Davis articulates a contractual model of the doctor-patient relationship, but whereas most professional contracts stipulate that fees are to be exchanged for services, Davis suggests that patients reciprocate their doctor's services by cooperating with the doctor's agenda during the clinical interaction, and complying with the doctor's recommendations afterward. Weibert and Dee portray a similar contractual model: having freely and of his own volition sought treatment the patient is thus compelled to follow the regimen. Both of these views of patient-doctor relations portray physicians as expert and compelling sources of medical assistance. For these authors, consulting a professional obliges the patient to follow that professional's advice, not to assess its appropriateness. The professional consultation signals the end of the patient's control over caring for the complaint--after the consultation the patient is responsible for following the directions received in the examining room. Van Camerik is more blunt: physicians' self-interest should cause them to give effective treatments, try to understand noncompliers, and avoid a damaged public image or malpractice suits.

These assumptions can be summarized as follows: the physician is the proper ultimate authority over the actions of his or her patients; in exchange for a physician's services a patient owes fees, cooperation, and compliance; noncompliance is usually the patient's fault; therapeutic partnerships are offered to patients by physicians, not vice versa; and patients exercise "free choice" in deciding to seek medical treatment and choosing a medical provider.

Origins of the normative view

Many of the assumptions just discussed are derived from the functionalist social theories of Talcott Parsons, especially his descriptions of the qualities of medical professionals (Parsons 1951, Chapter 10). According to Parsons, physicians manifest the following attributes as inherent parts of their social roles: they focus on performance and success rather than personal traits (Parsons calls this an emphasis on achievement rather than ascription); they emphasize similarities between disease manifestations rather than specific attributes of individual patients (universalism rather than particularism); they have a limited interest in health rather than all qualities of a patient (functional specificity rather than diffusion); they have a neutral emotional response to the patient (affective neutrality rather than affectivity); and they emphasize patient welfare rather than their own self-interest (collectivity orientation rather than self-orientation) (1951:433-436, 454-465). Parsons describes the functional significance of these attributes, emphasizing that each contributes to the scientific, rational, formal, commanding, privileged, and protected status of the physician in modern Western (and especially United States) society. He states that patient and physician cannot be treated as equals, for the patient must presume that the physician is technically competent, and must depend on that physician to resolve the health problem expeditiously (1978:449).

The second theoretical construct visible in these assumptions about compliance is Parsons' concept of the sick-role, the social obligations and exemptions faced by a person whose illness has been diagnosed by a professional healer. (See especially Parsons 1951, 1958, and 1975, and reviews by Kassebaum and Baumann 1965, and Levine and Kozloff 1978. Theorists since Parsons have considerably amended the sick role construct--their criticisms will be outlined later.) Parsons conceptualized the sick role as a problematic and short-lived status because society, if it is to continue to function, must regulate sickness. The sick role thus obliges a person to 1) want to get well, 2) seek competent help, and 3) cooperate with such help. It also exempts one from normal social role obligations, and from responsibility for having become sick.

These Parsonian views of the rights and responsibilities of patients and physicians are echoed throughout the preceding quotations: Evans' condescending description of the relative levels of understanding of patients and doctors; Davis and Weibert and Dee's descriptions of the differential rights and obligations of each side in the therapeutic encounter, and their implicit assumption that medical consultations come from choice; the assumptions of all that compliance is owed to the practitioner; and that the physician's expert advice will not cause the patient further problems.

The words of a leading compliance researcher explicitly link these assumptions with compliance: "...compliance with therapeutic regimens, as defined here, is a measure of how well individuals are integrated into the social system we call the health care process" (Barofsky 1977:31). This again shows the physician-centered focus of compliance: if a noncompliant patient is isolated from the health care process, then health care is synonymous with physician care. The next section explores how this view effects medical practice.

Clinical implications of the normative view of compliance

Researchers with what I have glossed as Parsonian assumptions use noncompliance like an epithet, obscuring the variability and denying the legitimacy of behaviors that differ from the clinical prescription. This process happens in clinical encounters as well, and has significant implications for patient care. When physicians label their patients "noncompliant" they distance themselves from their patients' actions, judging and labelling them rather than analyzing and understanding. Compliance is successful as a descriptive term in clinical practice precisely because its assumptions are hidden. A physician who calls her patient "noncompliant" need not consciously judge the patient to be combative or recalcitrant, although the label can sometimes substitute for these names. Even when it doesn't substitute for a derogatory judgment, the label "noncompliant" marks that patient's behavior as being outside the boundaries of a physician's responsibility. There is some of this already in medicine, in that physicians are not trained to recognize or deal with the social determinants or social impact of illness. Illnesses get treated rather than people: impoverished children become cases of lead poisoning, and rebellious adolescents or unconvinced consumers become noncompliant patients. This approach to compliance can cause it to become a reason for a physician to terminate a relationship with a patient. Conversely, though, it can also be a reason to invest more energy and time in a patient, to explore more completely the patient's rationale and therapeutic management goals.

At its most coercive, the compliance literature provides physicians with various ways to manipulate their patients' behavior without changing either their own beliefs or their patients' understanding (for examples of this, see Benfari et al. 1981, DiMatteo and DiNicola 1982, Rodin and Janis 1979). One example of this approach outlines how physicians can build up their own "motivating power", that is, their ability to make patients internalize the strategies they recommend, by using positive feedback and encouraging self-disclosure in their patients. The authors conclude with what is essentially a recommendation for researching how physicians can manipulate patients without being found out:

> Clients are just as aware of the norms of social equity as practitioners, and they are likely to be suspicious when given overzealous unearned praise or compliments. Practitioners' attempts to use acceptance can have boomerang effects if they give so much praise that they are presumed to be ingratiating with a hidden manipulative intent. The conditions under which acceptance by health-care practitioners will and will not be perceived as ingratiating by their patients need to be systematically investigated (Rodin and Janis 1979:76, my emphasis).

This is a call to seek the limits of medical deception, for it never acknowledges that "motivating power" is being increased precisely for hidden manipulative intent. It is one thing for a physician or other health care provider to teach patients techniques for self-assessment, behavioral change, and post-change continuity--this provides them with the tools to follow through with a professed desire to comply. Giving positive feedback with a coercive intent has been labelled unethical by some compliance researchers (e.g., Sackett 1976).

When noncompliant patients are viewed as those who have not accepted their part of the doctor-patient contract, then they can also be viewed as less entitled to physicians' time and skill. Continued access to medical care can be a real issue in noncompliance: for example, Davis and van der Lippe (1968) describe sanctions in the subsequent treatment of patients who discharged themselves against medical advice: 31% were prohibited from further treatment at the hospital and 54% were given no follow-up disposition. In a control group no patient was prohibited from further care, and "virtually all" were given follow-up dispositions to a private physician or a hospital clinic (1968:340). The label of "noncompliant" thus can carry real costs, such as difficulty in obtaining further medical care. It can also lead to legislative sanctions: under the laws of most states, seizures accompanying a physician-ordered anticonvulsant dosage change are not the resposibility of the patient, and will not cause a person to lose a driver's license, but seizures accompanying "noncompliance" will. An analogous process can happen to persons who bear the label "malingerer," which comes from clinicians judging that a claimed illness is being used irresponsibly for illegitimate social ends (see Szasz 1956).

Another clinical implication of the preceding view of compliance is that it provides practitioners with an empty label. Compliance is a term used to separate acceptable from unacceptable behavior. A patient who is compliant has followed a prescribed regimen, thus we "know" what that patient has done to take care of herself. But a patient who is NONcompliant usually is defined only by reference to what he or she has not done. A doctor might say "but I don't care what he has done if he hasn't done what I told him to do." This reflects one particular vision of proper doctor-patient relations, a vision which substitutes control for empowerment and information. This, bluntly stated, becomes: "Do what I told you, don't tell me what you did." But there are other possibilities: a physician might instead ask "if you haven't done what I told you, what have you done instead, and why?" This vision grants the importance of investigating behavior that differs from clinical advice, but still maintains the physician's role as questioner and evaluator. There is an even more egalitarian framing, which has the physician asking questions and offering his skills for use if the patient requests it: "if you haven't done what you told me you would do, what has interfered and how can I help you to deal with it now?"

These latter two examples reflect a vision of the patient-doctor relationship which substitutes an emphasis on communication for an emphasis on control. Thinking about patient behavior in terms of "compliance" in effect constrains communication by substituting a simple epithet for a complex act or series of acts.

Alternatives to the normative view of compliance

Some compliance researchers have developed clear ethical standards for their work (see, e.g., Jonsen 1979). Sackett (1976) proposes that in order to justify interventions to improve compliance the diagnosis must be correct, the therapy must do more good than harm, patient and physician must have mutual responsibility, and a patient must give informed consent to any strategy designed to influence compliance. Eraker et al. (1984) add that educating patients about compliance involves supplying both information and behavioral skills. If these have been provided but a patient still does not wish to comply, further attempts to change behavior should be stopped, and fear-provoking strategies avoided. This approach gives more autonomy to patients, and implies that their decisions about whether to comply are just as important and valid as physicians' decisions about whether and how to treat.

Early studies of compliance tended to perpetuate the ideological view of doctor-patient relations by examining patient characteristics (age, sex, income, ethnicity, knowledge, diagnosis) as independent predictors of compliance, but these characteristics commonly were not associated with compliance. Some studies in the past decade have focused on the Health Belief Model to explain compliance, examining patients' health motivations, their perceived vulnerability to illness, perceptions about the severity of the illness, and evaluation of the perceived benefits and barriers to acting (see Janz and Becker 1984). Evaluations of this model are mixed, with most support found for the effects of perceived barriers on compliance (Becker 1985), and criticisms directed toward the emphasis on patient beliefs to the exclusion of those of physicians and others (Leventhal 1985).

More consistent results have been found in factors such as degree of disability (positively correlated with compliance), and number of symptoms (negatively correlated with compliance); and in areas of referral lag (negatively correlated), quality of doctor-patient interaction (positively correlated), waiting time in the clinic (negatively correlated), duration of treatment (negatively correlated), perceived susceptibility to ill effects (positively correlated), and other psychosocial characteristics of patients or of patient-doctor interactions (Becker et al. 1979, DiMatteo and DiNicola 1982, Haynes 1979b, Hulka 1979, Inui and Carter 1985). These alternative perspectives examine physicians and patients together as a system, but they largely still limit their focus to doctor-patient interactions without going beyond them to the larger social world within which these interactions take place.

Many of these variables are situational rather than ascribed. In fact, rather than assuming that particular kinds of people are likely to be consistent noncompliers, it may be more productive to assume that all people are potential noncompliers. Each of us has our own distinct threshold after which we will seek new alternatives; our behaviors are prompted by unique catalysts. Therefore less research emphasis should be placed on particular characteristics (demographic, social, psychological, clinical) causing groups of people to self-regulate, and more attention should be paid to the situational constraints likely to make <u>any</u> person self-regulate. The essential question is not <u>who</u> does not comply, but rather <u>when</u> and <u>how</u>. Strategies of medication consumption are likely to change over time rather than remain constant, because people respond to new information and assess the results of previous regulation attempts.

To allow the variety within the single category of compliance to be conceptualized and measured, a number of words have been substituted for "compliance". For example, Weintraub (1976) suggested it was important to distinguish "intelligent noncompliance" and "capricious compliance." Noncompliance is intelligent when a prescribed regimen causes unanticipated or disabling side effects. Intelligent noncompliance is more desireable than capricious compliance because capricious noncompliance can cause medication levels and therapeutic effects to fluctuate excessively. Other authors have divided noncompliance into additional descriptive categories. Sherwin et al. (1973) discussed "consistent noncompliance," "excess consumption," and "partial or erratic consumption," while Trostle et al. (1983) outlined five categories of consumption: short-term excessive, consistent reduced, consistent excessive, sporadic, and substitutive.

The term "medication practice" has been suggested to encompass in a non-judgmental fashion the different ways physicians and patients manage medications (Schneider and Conrad 1983:183-4). The term "self-regulation" was put forward by the same authors to refer more specifically to medication consumption from the patient's perspective--people self-regulated their regimens if they: 1) reduced or raised the daily dosage of prescribed drugs for several weeks or more, or 2) skipped or took extra doses regularly under specific circumstances, or 3) stopped taking the drugs completely for three consecutive days or longer (1983:184). These restrictions helped separate those who had acted intentionally from those who periodically forgot. Using this definition Schneider and Conrad found that 34 of their 80 lower-middle class white respondents (42%) self-regulated their medications (1983:185). They did not break down this figure into the component categories, nor did they specify whether these actions had taken place during some specified interval before the interview, or at some unspecified time in the past. Nonetheless their study provides many important details about what it is like to take medication over time.

Taking pills is only one of a number of ways that people take care of themselves, though it is frequently the most visible way to deviate from a doctor's prescription--thus both "medication practice" and "self-regulation" emphasize the pharmaceutical side of the medical regimen. Self-medicating with drugs from prior prescriptions, taking vitamins, using other over-the-counter remedies, trying alternatives to biomedicine such as chiropractic, homeopathy, or spiritual healing--all these also are forms of self-regulating the treatment of one's illness. In fact following a medical regimen *also* could be called a type of self-regulation--in this case a patient decides to adopt the treatment suggested by the professional. If we give maximum autonomy to the patient then the only time a person is NOT self-regulating is when he or she is not in control: a person in an institution is unlikely to have the opportunity to self-regulate. Some regimens (e.g., those requiring sophisticated technology or assistance from medical personnel: kidney dialysis, hydrotherapy, physical therapy, surgical procedures) are by definition amenable to self-regulation only in the sense that they can be refused.

Origins of the alternative view

The physician-client relationship as viewed by these compliance researchers is more egalitarian than those presented earlier, but both groups still emphasize how central this relationship is to the various conceptions of what "compliance" means. These alternatives to the normative view of compliance have their theoretical bases in a series of critiques of the Parsonian model. Critics have argued, for example, that Parsons' model of the sick role has little application in chronic illness (Kassebaum and Baumann 1965, Bynder and New 1976). They also state that it relies too much on the physician as the ultimate labeller of illness, ignoring both the other members of the health team and the patient's lay referral system (Freidson 1961, 1975, Zola 1966, 1973); it misses the controlling power of the profession of medicine, and the effects the profession itself has had in forming the image of physicians in this society (Davis 1960, Freidson 1970, Zola 1972), and it pays no attention to the political and economic context of the physician-patient relation ship, especially the impact of class stratification (Waitzkin and Waterman 1974, McKinlay 1978). Anthropologists have criticized the cultural biases of the model, particularly its neglect of alternative sources of healing (Chrisman 1977, Eisenberg 1977a and 1977b, Kleinman 1980).

Freidson has stated that the doctrine of free patient choice is what places the burden of compliance on the patient. (This doctrine is exemplified in the words of Weibert and Dee [1980:9], "Just as he decided to seek treatment, so he must decide to take his drug correctly...") People seek care from physicians in many instances because physicians have become "gate-keepers," that is, the sole legitimators of claims that one is <u>really</u> ill and therefore deserving exemptions from normal social responsibilities (school, work, other customary duties). They also seek care from physicians because physicians have sole legitimate access to many treatments, a hallmark of what has been called medicine's "monopolization," defined as the unique ability to direct who will utilize particular domains of knowledge and technology. Physicians control access to a broad range of "prescription" medications, and must be consulted to obtain these medications. The doctrine of free patient choice is therefore a false doctrine: one cannot really "choose" a particular source for an exemption from social tasks when there is only one source available. There can be no even exchange between clinician and patient when one cannot withdraw from the relationship or stipulate its terms.

Even if it were equally easy for each side to withdraw, the doctor-patient relationship frequently would still be problematic. Physicians tell patients to fend off the onslaughts of medical conditions that sometimes are invisible, and ask them to take medications that cause side effects. They spend little time with patients (in 1980, almost 75% of patients spent less than 15 minutes with a doctor per visit [U.S. National Center for Health Statistics 1982:7]), and yet they often have to convey complex information and request major behavioral changes. Freidson and others have emphasized the way physicians use ideology to justify and expand their persuasive abilities. They can rest the legitimacy of their advice and actions on the authority of their status as professionals, and thus avoid the need to present evidence for their claims and requests. They neutralize potential threats to their status by insisting that patients must have faith in them (1970:105,120,142-3). More recent sociolinguistic research has demonstrated the variety of speech patterns and conversational styles employed by physicians to achieve their own therapeutic goals. For example, Wallen et al. 1979 (cited in West 1984) found that less than one percent of the total time spent in information exchange between doctors and patients is devoted to physician's explanations to patients. Waitzkin (1985:89) found that the mean time spent by doctors in information giving was nine percent of total interaction time, while doctors estimates of this time were almost seven times greater; patient questioning took about one percent of the total time. Using conversational analysis West estimated that two thirds of the interruptions in transcribed clinical interviews were initiated by the physician, and one third by patients (1984:56); physicians also asked 90% of the questions (1984:80).

In sum, the alternative view of compliance pays more attention to assessing the respective contributions of both doctor and patient to the clinical encounter. Physician-centered variables such as communication skills, age, practice size, and the like form one part of the explanation. Another part is composed of interaction variables, the outcomes of differing behavior and expectations between the two parties in the clinical exam. And the third part is taken by patient-centered variables like illness type, social class, social support, and similar characteristics.

Clinical implications of the alternative view of compliance

This alternative view of compliance provides more power and autonomy to people when they are patients. It emphasizes the value and legitimacy of negotiating a particular set of management strategies, and of setting out in advance patients' and physicians' goals, obligations, and evaluations. It provides a more even scenario for exchanges between patients and physicians, one where either side can withdraw, and either can stipulate terms. Rather than blaming the physician as a manipulative technocrat, or the patient as an incompetent naif, this view better accounts for physician-patient discord: patients who seek authoritarian physicians react poorly to power-sharing physicians, and physicians who seek submissive patients may be startled by the egalitarian questions of their consumerist patients.

The normative view of compliance results in a physician-centered analysis of the therapeutic relationship. I said that this view can 1) cause physicians to label patients' behavior rather than explain it; 2) help physicians to justify using manipulative strategies on their patients; 3) lead to negative sanctions and reduced access to medical care, and 4) emphasize physician control to the neglect of physician communication. The alternative view divides compliance into a series of component parts, emphasizing the diversity of behavioral strategies, and their rationality. It emphasizes negotiations and contracts rather than control, and implies that either party can withdraw from the doctor-patient relationship.

There is yet a third way to look at compliance, which emphasizes the patient's point of view but includes factors leading to and from a physician consult. Before examining this third viewpoint, however, I need to set the stage for how "compliance" came to be an important topic in contemporary clinical research and practice.

TOWARD A SOCIAL HISTORY OF COMPLIANCE

Changes in the concept of compliance parallel changes in the nature of the doctor-patient relationship, yet to date there has been no historical work done on the topic of compliance, except for a few cursory paragraphs relying on a standard set of anecdotes. For example, compliance researchers commonly cite Hippocrates as their progenitor because he is reported to have said that "[The physician] should keep aware of the fact that patients often lie when they state that they have taken certain medicines" (Haynes 1979a:3). They also quote the renowned 19th century clinician Sir William Osler, who wrote that "The desire to take medicine is perhaps the greatest feature which distinguishes man from animals"

(Cushing 1925, cited in Becker and Maiman 1980:130). These, together with the reference to the Garden of Eden, are about all the history there is.

Compliance researchers have explained the growth of their literature by linking it to the development of antibiotics in the 1950s, and the subsequent wide availability of these effective treatments. Authors like Robbins (1980:703), Bissonette and Seller (1980:41), and Haynes (1979a:4) write that while noncompliance may have been occurring since the time of Hippocrates, only in the 1950s did physicians obtain many truly effective medications for the first time, and only then did it became as important for physicians to make sure that these medications were <u>consumed</u> by patients as it was to make sure they were properly chosen and prescribed.

This explanation mistakenly assumes that scientific measures of clinical effectiveness are the foundation of professional beliefs about clinical effectiveness. It is plausible but incomplete, since it fails to acknowledge that most healers in any historical period (be they physicians, bone-setters, barbers, surgeons, or shamans) believe in and reinforce the curative efficacy of their treatments. Physicians in the 18th and 19th centuries relied on their so-called "heroic treatment," which consisted of bleeding, purging, mercurials, and blistering. Dissenting voices were raised, such as one 18th century Scottish doctor who said that occasionally "nature gets the better of the doctor, and the patient recovers" (Douglass 1760, in Duffy 1978:132), or a remark by Oliver Wendell Holmes in 1860 that "I firmly believe that if the whole <u>materia</u> <u>medica</u> as now used could be sunk to the bottom of the sea, it would be all the better for mankind--and all the worse for the fishes" (quoted in Crout 1980:41). But by and large these earlier physicians and healers also believed in the therapeutic effects of their ministrations, and they probably were just as concerned about compliance as any contemporary physician.

A good mid-19th century example of this concerns treatment for epilepsy. W.R. Gowers, a respected physician of the day, explained that noncompliance sometimes caused a patient's seizures to become _more_ severe after treatment had begun:

> A very frequent occurrence is, that a patient, after a few months' freedom from fits, discontinues the medicine and relapses. He comes again; the fits are again stopped, but less readily than before, again he quits the treatment and the attacks recur, and are not completely arrested (Gowers 1964 [1851]:211, quoted in Wannamaker et al. 1980:157).

Thus in 1851 Gowers plainly believed that his treatments were effective, and that seizure recurrences were caused by noncompliance. He saw patient behavior, not medication, as the culprit a full century before antibiotics.

The history of compliance is still immature. A social history of compliance must take its material from the history of cultural beliefs in curative substances, and the history of the profession of medicine, as much as the history of pharmaceuticals. The documents for this history can be found in legislation, medical journals, and advertisements that address and reveal the self-image of the medical profession. Such a history is valuable for portraying the origins and growth of contemporary concerns about compliance: rather than a technology-driven phenomenon of the last three decades, compliance concerns are a phenomenon of the last century, driven by the growing monopolistic power of the medical profession.

Most of the literature on compliance has confused faith in drugs with faith in physicians. For example, the modern chronicles of compliance have missed a point made by Owsei Temkin, a historian of medicine, who once pointed out that patients have had faith in drugs for longer than they have had faith in physicians (Temkin 1964). The compliance literature suggests that the relationship between physician and patient is--and by inference, should be--the most important factor determining the course of a person's health-related activities. Yet Temkin says that obtaining the medical products now available (primarily if not solely from physicians) may be more important to patients than their relationships with physicians. Physicians are a historically and geographically bounded form of labor organized to provide health care, but the consumption of substances to cure illness has no such boundaries. Labelling patients "noncompliant" because they follow their own ideas about their own care misses the fact that this is what people have done since medicines were first used. The word "noncompliant" is applicable only within a particular historical and cultural context. Those who use it mistakenly equate health care dominated by physicians--a specific outcome of a contemporary power distribution--with health management in general.

Compliance research thus makes a crucial historical error. It places undue emphasis on one particular historical relationship between healers and the afflicted, the physician-patient relationship, and neglects the existence of more universal forms of obtaining care: self-management, or relying on family, friends, neighbors, and others (Eisenberg 1977b). The very notion of compliance requires a dependent layperson and a dominant professional--someone to give orders and someone to carry them out. Yet the structural dominance of the medical profession is not a timeless or universal phenomenon. It depends on 19th and 20th century legislative acts that helped to establish the "monopolizing" and "gate-keeping" functions of medicine I outlined earlier; things like controlling who may practice the profession and where (licensing of practitioners and educational establishments, malpractice review), who has access to and control over scarce valuable items like pharmaceuticals (controlled substance laws), what reasonable levels of payment are (Medicaid, Medicare), how much is known about costs and charges (restrictive advertising covenants), and a host of other structural constraints (Bosk 1979, Brown 1979, Duffy 1984, Freidson 1970, Klein 1973, Morrow 1982, Starr 1982, Stevens 1971.)

Compliance in the medical realm is also predicated on the historical emergence of regimens which were not directly performed by the professional on the client, but rather were left up to the client's volition. There is, for example, little reason to discuss patient noncompliance in surgery. Noncompliance is possible where there is freedom to choose: surgeons encounter it in post-surgical recovery regimens, while internists see it in medication and diet regimens. This distinction applies also to non-biomedical forms of treatment: bone-setting, massage, singing (as practiced e.g., by the Navajo), and spiritual healing all act directly on an afflicted person. Compliance in the sense of following a culturally-empowered specialist's advice is relevant only where materials or behaviors are suggested to ill persons or their kin to be prepared, consumed, or performed later. Compliance in urban North America usually refers to taking medications as ordered; in rural Africa, Asia, and Latin America it may also mean preparing and drinking teas as ordered, or performing specific ritual activities at "prescribed" times and places.

These points are fundamental to the perspective of medical anthropology, for the foundations of this subfield are that 1) disease is universal; 2) human groups develop methods and assign roles to people to deal with disease; 3) they also define and think about diseases using particular sets of beliefs, attitudes, and values (Polgar 1962, Wellin

1977). Diseases and the techniques used to treat them are culturally constructed categories that vary from place to place. In many areas of the world where biomedical practitioners are recent arrivals on the therapeutic scene, residents use both biomedical and traditional healers to attain relief from their afflictions. This was first called the "dual use" of traditional and biomedical practitioners (Simmons 1955, Press 1969), and has been more recently described as the "pluralistic" use of multiple medical systems (Leslie 1980). Culture influences which symptoms are selected for treatment by healing specialists, as well as which specialists are appropriate. Chrisman (1977) labelled this the "health-seeking process," and applied it to the contemporary United States. Romanucci-Ross (1969) described "hierarchies of resort" in decisions about what healing specialist should be approached in Melanesia, and Young (1981) developed a model of decision-making based on use of plural medical resources in rural Mexico. Janzen (1978) described the impact of kinsmen and associates serving as "therapy managing groups" or brokers between sufferers and specialist healers in Africa. The following sections follow this medical anthropological tradition by analyzing the context of service use and disease management in United States white middle class culture. This requires viewing a physician visit even in the United States as one of many possible choices about where to obtain care, and requires analyzing rather than taking for granted the cultural importance of the physician in health care.

Rather than pointing to the efficacy of antibiotics to explain the growth of a concern for noncompliance with therapeutic regimens in the United States, one might point instead to the development and consolidation of the profession of medicine, and the growth of the pharmaceutical and proprietary drug industries. Advertising in medical journals documents these changes, for it portrays strategies that directed information to physicians rather than to patients, reinforcing physicians' beliefs that they were not only the best but the sole proper source of care for their patients. A selection of advertisements from campaigns for infant feeding materials conducted in the 1930s shows the development of a new professional and industrial concern for controlling the behavior of the sick. These advertisements help trace how a concern for market control combined with a concern for therapeutic power, and evolved into a concern for patient compliance. For much of the 19th century physicians had little power: they were poorly trained and disorganized, and had little social prestige. During this time patent medicine companies advertised their products to the general public. ("Patent" is a misnomer: their ingredients were copyrighted and thus private, rather than patented and public.) However, as physicians organized and became more powerful, these companies began to direct more advertising to physicians. The next section documents these changes, and links them to the growing significance of patient compliance.

Nutritional supplements and infant formula: transforming information control into patient compliance

The late 19th century had seen many miracle cures touted as cheap alternatives to medical care. At the beginning of the 20th century both organized medicine and the United States government began to legislate changes in the extent and kind of drug advertising to the public. The government passed a series of laws between 1906 and 1929 regulating various aspects of medicine advertising and labels. The American Medical Association stopped accepting patent medicine advertisements in its Journal in 1905, and began to rule on whether various products should be accepted for use. In 1924 it reserved the right to reject advertising for approved drugs from companies that derived earnings from other unapproved drugs. Though physicians and politicians campaigned against misrepresentation of health products, they did so with somewhat different goals: the government meant to make consumer information more accurate, while the AMA wanted to control the amount of information consumers received, and thereby increase physician control over medicines (Apple 1982, Starr 1982:130-134).

Physicians began in the early 20th century to consolidate their control over the business of healing in the United States, and began to pay more attention to ways in which they could maintain their professional standing and increase the breadth of their practices. This was paralleled by the growing public health movement in the United States, which argued for improving (and controlling) the collective health of the country by means of population interventions like putting iodine into salt, or still later, fluoridating water. One early strategy in doctors' attempts to control patient behavior was to sell food products containing nutritional additives, thereby, at least ostensibly, circumventing patients' problems in taking nutritional supplements as suggested. For example, the following text accompanied a 1934 advertisement in the Journal of the American Medical Association, which promoted evaporated milk with cod-liver oil extract added.

> YOU FORGOT again MOTHER. Yes...mothers <u>do</u> forget!
>
> How many mothers forget to give regularly the cod-liver oil you prescribe? Many doctors are now recommending DEAN'S so that the children under their care are assured a regular and definite supply of Vitamin "D".
>
> DEAN has put Vitamin "D", extracted from cod-liver oil (by the Zuckerman process), into evaporated milk. And you can't even

> taste it. Furthermore, DEAN'S is pure, selected, cow's milk from tuberculin-tested herds, unsweetened and evaporated to double richness. Developed especially for infant feeding, DEAN'S is also important in child and adult nutrition. We should like to send you Vitamin "D" Evaporated Milk Literature and a Standard Feeding Formula. May we? (JAMA 102(4):33)

Adding nutritional supplements to food products is a problematic strategy: on the positive side the benefits of the supplement accompany the consumption of the food product, and no extra pills or syrups need to be taken. On the negative side, doctors can rely on a fixed proportion of the additive being consumed only <u>if the food product is consumed according to directions</u>. The product provides the additive but does not require the continuing supervision of the physician. This was an economic hazard to the physician because it did not require return visits. But these products could be misused by patients: physicians gained control over return visits by emphasizing the medical hazards to a patient, and thereby avoided focussing on the economic hazard to their livelihood.

The potential problem was solved for infant formula preparations in a way that increased physician control over patient behavior and increased formula company revenues. It was simple and elegant: preparation directions and feeding schedules were taken off containers of infant formulas, and advertising was directed at physicians rather than the lay public. Consumers of the product could obtain and consume it only under the care of a physician.

This change took place in a time of increasing government regulation, when infant formula companies decided to entrust physicians with control over their products. (This has been labelled the 'ethical push' route for advertising, while the 'consumer pull' strategy is to advertise in the mass media directly to the public.) Physicians would be more respectable and profitable salesmen; as time passed their control over the distribution of certain health-related products began to appear natural and necessary. The sales strategy was expanded from vitamin supplements to infant feeding formulas, and became the model for subsequent marketing of so-called "ethical" pharmaceuticals. (For a recounting of the history of the formula-marketing decision see particularly Apple 1982.) We see this strategy forthrightly articulated in a half-page 1931 advertisement from the Journal of the American Medical Association, the complete text of which is reproduced below:

> The present spectacle of vitamin and irradiation advertising running riot in newspapers and magazines and via radio emphasizes the importance of the physician as a controlling agent in the application of vitamin products.
>
> Mead Johnson & Company feel that vitamin therapy, like infant feeding, should be in the hands of the medical profession, and consequently refrain from exploiting vitamins to the public. (JAMA 96:32, 1931)

This same strategy appears in a full page advertisement in the same journal, which concludes with the following paragraphs:

> When the physician reads this class of exploiting advertisement which patronizingly refers to his endorsement of the most ridiculous claims, and later hears his patients knowingly repeating these to him, he cannot help asking himself these questions:
>
> (1) Should the layman receive his medical education, including his vitamin-mindedness, from the commercial house, or from his doctor?
>
> (2) Should the commercial house exploit vitamins in modern patent medicine style, or should the physician control their intelligent application?
>
> Mead Johnson & Company, for one, continue to feel that vitamin therapy, like infant feeding, should be in the hands of the medical profession, and consequently refuse to lend their aid to exploiting these valuable agents to the public. This house, for one, advertises its vitamin products exclusively to the medical profession and furnishes no directions to the public. (JAMA 96:46, Aug. 22, 1931)

This deliberate decision to advertise a marketing strategy was effective because it reflected and amplified a sentiment already common among U.S. physicians. That sentiment was formalized in 1932, when an American Medical Association Committee passed a resolution requiring infant food companies that wanted A.M.A. approval of their products to advertise those products only to physicians. These particular advertisements clearly go beyond infant feeding, addressing vitamin therapy as well. But what is most interesting about them is that an ideology of physician control itself is being created and promoted here; an explicit announcement of support for physician control is used to sell products.

We see another example of the ideology of physician control in a third 1931 advertisement by Mead Johnson & Company. This full-page drawing from the Journal of the American Medical Association portrays a physician in profile in the foreground, examining a large paper headed "Pediatric Case History". In the background are a woman and her child, who are looking at the physician (and the back of the paper) with trusting expressions. The message being examined by the physician reads in its entirety as follows:

> The Mead Johnson Policy of cooperating exclusively with physicians by refraining from suggesting or indicating the application of Mead's infant diet materials to the laity assures the patient's fullest cooperation with the physician. (JAMA February 7, 1931 p. 74)

This advertisement also supports creating and maintaining physician control over patients. It promotes a company's products by associating them with a policy of advertising only to the profession. It also points out the professional benefits that accrue from having physicians control health-related information. But rather than employing the stark unadorned text of the last advertisement, this advertisement also presents an idealized image: the doctor is drawn as the active provider of care, the patient as passive (and grateful) recipient. This is a telling portrayal of the marketing strategy of the producer, but it is also a snapshot of an image-making process in action. By controlling information, the medical profession gains power. By withholding information it promotes passivity and dependence.

These examples of 1930s infant feeding advertisements demonstrate that: 1) a concern for controlling patient behavior antedated the development of antibiotics; 2) the U.S. medical profession's interest in maintaining control over patients' behavior and access to information was recognized and reinforced in the 1920s and 30s; 3) professional self-interest was a significant factor in the movement to limit popular advertising of infant feeding products and of vitamins; and 4) the contemporary concern for "compliance" was openly articulated earlier in this century as a concern for patient "cooperation" and physician "control."

The evolution from a concern for "control" to a concern for "compliance" can also be seen more recently in the changing headings used by the Index Medicus to categorize the literature on patient behavior. "Patient Compliance" first appeared as a medical subject heading in the Index Medicus in 1975, and was cross-referenced under the heading "Patient Dropouts" until 1981. In 1981, "Patient Dropouts" was replaced by the heading "Patient Non-Compliance". In contrast the term "Self Care" first became a heading in 1968, but until 1981 referred only to rehabilitation. Only in 1981 was it first used to categorize health behavior not oriented to physicians.

Compliance is a cultural phenomenon intimately connected with the self-image of physicians, and with their organized (and successful) attempts to define the limits of their own discipline. Yet the present level of respect and power accorded physicians is of recent origin, and already shows signs of waning. Only in the past century have physicians exercised their present monopoly over medical technology and pharmaceuticals. Now for-profit hospitals and medical groups are employing physicians as salaried workers; their growth is causing this monopolistic power to wane (McKinlay 1978, McKinlay and Arches 1985, Starr 1982). Physician control over the technology of medical care is starting to diminish as pharmaceutical companies lobby for the right to advertise directly to consumers, the Food and Drug Administration moves drugs (such as cortisone) from prescription to non-prescription categories, and Health Maintenance Organizations develop lists of approved medications. But how total has physician control over health care ever been?

UNPACKING COMPLIANCE INTO COMPONENT PARTS

Until now I have examined the history and implicit assumptions behind the topic of compliance. This section treats compliance as one among many factors operating in the relationship between physicians and patients. As we have seen, critics of the compliance literature have said that it places too much emphasis (and blame) on the habits of the patient (e.g., Garrity 1981, Hayes-Bautista 1976a, Stimson 1974, Udry and Morris 1971, Zola 1981b). However, only a few have argued from the position that the biomedical system is but one potential source of care, and that patients seeking cures may be more faithful to their search than to the suggested regimens of one particular source.

If health-seeking is seen as a continuum from noticing symptoms to finding relief, then physician consults can be seen as brief and sporadic events in an ongoing process. Noncompliance then becomes a context-dependent label, since it defines patient behavior according to physicians' standards and expectations. What matters from the patient's perspective is that health-seeking leads to health: for someone with an acute illness this may mean a cure, while for chronic illnesses this may only mean satisfactory care. In either case patients who feel that their search is making progress will risk the momentary noncompliance label <u>if</u> in their judgment the physician's regimen interferes with their health or social life.

Compliance critics have often objected to the word's connotations of patient powerlessness and physician domination (e.g., Hayes-Bautista 1976a, Jonsen 1979, Stimson 1974, Trostle et al. 1983, Zola 1981b). Objections to compliance extend beyond the word, however, because as we have seen, the compliance literature encompasses a broad series of beliefs and attitudes about physician power, the proper behavior of the afflicted, the way to change this behavior, and the sources of friction in patient-physician encounters. The word "compliance" is useful insofar as it reminds us of these beliefs and attitudes, but when it masks its ideological charge it perpetuates a physician-centered vision of physician-patient relations. Then the word itself must be questioned. Research under the rubric of compliance has reproduced but not resolved the problematic nature of doctor-patient interaction.

The most important problem with compliance research is that it usually lumps many different behavioral strategies under a single global heading. When people "explain" noncompliance they lump a potentially infinite series of acts under a single heading, but this heading exists in the first place only because the behaviors that comprise it do not conform to accepted professional medical wisdom. When compliance is defined physiologically, by whether a medication's serum level is adequate, little attention gets paid to the various factors that might cause levels to be non-therapeutic. This has caused some compliance researchers to adjust their methods rather than resolve their conceptual problems, for example a Minnesota study of noncompliance found differences between people taking excessive and insufficient levels of medication, and then excluded the cases with excessive medication levels from their analysis. The compliance research has been successful in pointing out that patients commonly do not follow doctors orders, however, it has not explained what people do when they don't follow a doctor's clinical prescription.

Noncompliance: the patient's point of view

Managing any illness, but especially a chronic one, consists of many different activities, some properly called strategies by virtue of their coherence and conscious design, others better called incidental actions. As I have said, many of these behaviors have different motivations: some are designed to alleviate symptoms, or cure a disease, others explain why one bears this particular affliction, reduce the impact of the affliction, or lessen the ill effects of other supposed health-enhancing treatments. Since the existence of the physician is so crucial to the concept of compliance, factors affecting the relationship between physician and patient should also be important: subtleties of communication, emotional reactions, and whether a physician's image and behavior accords with a patient's expectations.

From the patient's point of view, consultation with a physician is one step in what can be a long journey to relieve suffering (Eisenberg 1977b, Kleinman et al. 1978, McKinlay 1981, Stimson 1974). The process begins with noticing symptoms, and judging that they deserve some care. It continues with seeking information from family, friends, co-workers, and media like books, journals, television, and the like. This information can be about the symptoms, the condition thought to bring them on, appropriate places to treat the condition, or comparisons of various resources. Then these resources are assessed for cost, availability, appropriateness, familiarity, and quality. If a physician is consulted as one resource, this does not mean that the process stops--in some cases physician consultations can impel the journey forward, as diagnoses are rejected, or treatments found to cause more harm than relief.

While most analysts of patient-doctor relations have emphasized the power of physicians to satisfy their agenda, insufficient attention has been paid to the power of patients. While their power is as yet neither as strong nor as monolithic as that of physicians, patients nonetheless have many kinds of potential and actual power in their relationships with physicians. Political theorists have noted that the consent that legitimizes power also reduces its control (Balandier 1970). Though it seems paradoxical, the collective power of patients is based at least in part in the power of physicians: patients' consent is necessary if physicians' power is to be legitimate, and the actual or threatened withdrawal of this consent can change physician behavior quite dramatically. When the legitimacy of biomedical intervention in birth was questioned, for example, physicians began to change their treatment of the birth process and decrease their interventions. Another collective manifestation of patient power is the growth of the consumer movement in medicine: this movement rejects the primacy of physician expertise and the necessity of patient cooperation, substituting instead the radical notion that medical care is a commodity to be rated, shopped for, complained about, and regulated.

The power of patients can be seen individually as well as collectively, for example in their abilities to select, discard, supplement, or follow particular medical regimens. To some extent patients can shop until they obtain the diagnosis or treatment they seek. They are not compelled to follow the regimen suggested by any one source, and can pick and choose as long as they can afford to pay. They can also adapt their clinical histories to fit their treatment preferences, or give particular kinds of gifts to physicians (Drew et al. 1983, Hayes-Bautista 1976b, Long 1980). They have allies in hospitals anxious to cut costs, increase patient satisfaction, and increase market share; and in lawyers eager to file malpractice suits. They can use physicians to bolster the legitimacy of their claims in other realms, for example in employment disability claims. (This is a favorite topic of sociologists: see Brody 1980, Haug and Lavin 1983, Haug and Sussman 1969, Kelman 1976, Reeder 1972, Sawyer 1980. Anthropologists have also recently contributed to the analysis of patient controls in medical practice: Estroff 1979, Scheper-Hughes and Locke 1987, Taussig 1980.)

From the patient's point of view, choosing to seek medical assistance brings no necessary injunctions about whether one follows that advice. Seeking care from a physician also does not preclude seeking other sources of care. Other sources include specialists in other forms of treatment, such as chiropractors, religious healers, alternative medical texts, and the like, and also non-specialists (family, friends, coworkers, or neighbors) who might offer health-related advice. There is now a large and growing literature on this topic, which has recently been called "self-care". Sociologists have called it "illness behavior" (Mechanic 1962) when it takes place before a biomedical diagnosis, and "sick role behavior" when it takes place afterward. Anthropologists have been less bound to professional legitimization, using concepts like "health-seeking behavior" (Chrisman 1977) to encompass attempts to find relief from illness from biomedical <u>and</u> non-biomedical practitioners.

With attempts to reduce federal involvement in health care, self-care is getting increasing amounts of attention (Dean 1981, Levin 1980). It is also pushed by the over the counter (OTC) industry, and appears to be an important but largely a middle class phenomenon in the United States (Kroeger 1983). Analysts have asked whether self-care is being touted to legitimize reductions in government health services, or to reduce the perception that illness is a social responsibility, and increase the perception that it is an individual one (Kronenfeld and Wasner 1979, Robinson 1980).

The history of medicine (but not the history of health care) in the United States is the history of professional control. North Americans have a truncated set of options for professional medical care when compared with people in other cultures. Homeopathy has been relegated to the fringes of biomedicine, osteopathy has been merged into professional medicine, and only chiropractic still exists as a direct competitor with biomedicine--and then usually for specific complaints like back pain or a variety of conditions thought to come from "nerves" (Kane et al. 1974, McCorkle 1961).

While the history of medicine is the history of professional specialization, the history of health care includes non-professional sources of care, self-medication, and the like. There has always been a large market in the United States for non-professional medical treatment in the form of "proprietary," OTC, non-prescription medications. The first American advertisement for a proprietary medicine (Daffy's Elixir

Salutis) appeared in newspapers in 1708 (Young 1974). In this country today medications are divided into OTC preparations available to anyone without a prescription, and so-called "ethical" pharmaceutical preparations available only with a physician's prescription. By the mid-1970s the Food and Drug Administration estimated there were about 350,000 OTC products on sale in the United States (Ibid.:29). In contrast, the Physician's Desk Reference, a compendium of manufacturer's information about prescription drugs, contains information about some 2,500 medications. The size of the OTC estimate shows the size of the industry and helps explain the degree of difficulty the government has in regulating it. Americans face a wide choice of available preparations to manage their illnesses themselves.

Compliance studies and numbers of OTC preparations are only two pieces of evidence that self-management strategies are ubiquitous in America. A large national survey (National Analysts Inc. 1972) revealed the following health-related beliefs and practices in this country: 75% of adult Americans believe that extra vitamins provide more pep and energy, and 26% reported using nutritional supplements, without a physician's advice, expecting observable benefits. (This last finding was duplicated by another national survey in 1979, which found that 27% of the men and 40% of the women surveyed reported they regularly took vitamin pills or other vitamin supplements [Schoenborn, Danchik, and Elinson 1981:11].) About half the respondents in the 1972 study were concerned with reducing or avoiding weight gain, and 8% followed dieting practices that were questionable by medical standards; nearly 2/3 believed that a bowel movement is necessary every day for health, and 2% said they took a laxative every day or nearly every day; 12% reported they had chronic conditions (e.g., arthritis, asthma, diabetes, heart trouble) never diagnosed by a physician; and about 20% had been to a chiropractor. These are only a few manifestations of what the authors labelled the "rampant empiricism" guiding the health practices of the American people (1972:83-84). The study's authors clearly felt that most, if not all, of these behaviors were questionable by medical standards.

Larger estimates of the extent of self-care in this country were provided in a survey by the Simmons Market Research Bureau (1981). This study asked about a series of illnesses or symptoms experienced over the past year, and then asked whether OTC products were used. To give some idea of the range, 15% of the adult respondents reported having arthritis or rheumatism, and half of these said they had used OTC products as treatments; 3% said they had asthma and 39% of these had used OTC products as treatment; 59% had had headaches and 74% of them had used OTC treatments. More than a third (36%) of respondents said they were presently controlling their diet, 6% with OTC products; 6% of respondents said they used laxatives once a week or more often; and 12% said they used cold, allergy, and sinus remedies once a week or more often. An international comparative study of health service utilization reported that 37% of people in the United States had taken an OTC product within a 2-day period (Kohn and White 1976).

The most commonly sold categories of OTC products are cold remedies, antacids, and laxatives, and the market value of OTC products sold in the U.S. in 1982 was 6.7 billion dollars (Advertising Age, July 4, 1983). Judging by these figures alone, quite aside from the surveys, a high proportion of Americans self-treat their common ailments.

Given the increasing popularity of self-care in this country, and its potential for reducing physicians' market share, one would think that physicians would have strong opinions about it. What do physicians think about patient self-care? A questionnaire mailed to Los Angeles physicians found that over half the respondents felt that self-care would <u>not</u> reduce doctor visits and might create more harm than good; and that people cannot, should not, and do not want to learn to take care of themselves adequately (Linn and Lewis 1979). From 25 to almost 50% favored various aspects of self-care. (The results are based on a 36% response rate--one can only speculate about the attitudes present among the many nonrespondents.) This suggests there is room for considerable conflict between physicians and patients on the topic of self-care, which can result in terminating the patient-doctor relationship.

Another name for terminating is doctor-shopping, defined as switching physicians for reasons other than migration, physician death or retirement, or physician referral (Hayes-Bautista 1976b, Kasteler et al. 1976, Lazare et al. 1975). This can be considered another aspect of self-care, and it, too, appears to be increasing. With the rise of consumerism in this country patients appear to be more willing to shop for satisfactory medical care just as they shop for groceries: one study in Salt Lake City found 48% of high income families and 37% of low income families had shopped for doctors in the past, and 4% within the past year (Kasteler et al. 1976, Olsen et al. 1976). Norman Cousins did an informal community-based questionnaire survey in the UCLA area on the topic of patient-physician relations. Eighty-five percent of respondents said they had either changed physicians in the past five years or were thinking of changing "for reasons other than relocation, the physician's retirement or death, and so forth." Physician incompetence was cited by 25% of those who switched, while most cited physician's style or personality, including complaints about poor communication, offensive personal habits, disorganized offices and the like (Cousins 1985). In Haug and Lavin's U.S. population study, one in six respondents said they were not as inclined to accept a doctor's opinion as they had been in the past, and two thirds of the primary physicians interviewed in a state sample survey thought patients were more likely to challenge their authority than previously (1983:83). It seems that some aspects of self-care are likely to cause fewer visits to physicians, while other aspects are likely to bring more conflicts during the visits that do occur.

George Bernard Shaw, who was no friend of the medical profession, bluntly pointed this out: "The doctor may lay down the law despotically enough to the patient at points where the patient's mind is simply blank; but when the patient has a prejudice the doctor must either keep it in countenance or lose his patient" (1911:66).

Physicians on the whole appear to disapprove of self-care among patients, assume they can do better at treating their patients' ailments, and think their patients are getting more rebellious. But when they do see patients in their examining room, physicians commonly <u>underestimate</u> their patients' knowledge about medicine (M. Davis 1968, Gordis 1979). One early study found that 81% of physicians surveyed had tended to underestimate patient knowledge (Pratt et al. 1957:1280). More recent studies have confirmed this, e.g., Ordoñez Plaja et al. 1968 and McKinlay 1975. In addition to underestimating patient knowledge, doctors also underestimate patients' desire to receive more information. Analyzing audio and/or video recordings of 336 medical encounters from a randomly chosen group of diverse medical practices, Waitzkin found that 34 physicians underestimated patients' desires for information in 65% of encounters, overestimated them in six percent, and correctly perceived them in less than a third (1985:90). This difference can be seen in the more fundamental area of access to one's medical record. In a Midwestern state 72% of a sample of patients agreed they should have the right to read their own medical record, while only 35% of a sample of physicians from the same communities felt patients should have that right (Haug and Lavin 1983:66-67).

These studies show that there are significant disjunctions between expected, desired, and actual levels of knowledge when groups of patients with diverse illnesses and their physicians are compared. Part of the responsibility for this rests on physicians, who have become better trained to interpret test results than to converse with their patients. To stop at this, however, counts as "doctor-bashing," blaming physicians for all the ills of the medical system. The problem is more complex than physician conspiracy theories can handle. Institutions have put considerable pressure on clinicians to spend minimal amounts of time with patients, and insurance and legal constraints have required physicians to order more medical tests for their defensive practices. In a sense, the medical profession's image enhancement has backfired: patients have come to expect their physicians to be infallible experts, and they forgive fewer mistakes or unexpected problems.

Given the seeming pervasiveness of misunderstandings between patients and physicians, it should come as no surprise that such problems have also been found between neurologists and their clients with epilepsy. A well-designed survey of these groups found many differences between what neurologists reported doing about drug selections and what patients reported wanting: while the benefits of a proposed drug were sought by most patients and disclosed by most neurologists, they were not at all in agreement about risks. Parents of pediatric patients wanted to know an average of seven risks more than pediatric neurologists reported disclosing, and adult patients wanted to know nine more. More than 80% of patients and parents wanted to be told about alternative drugs, while only about half of neurologists reported routinely telling about alternatives. More than half of patients and parents thought they should make the final decision about whether and what medications to take, while only a third of pediatric neurologists and less than 10% of adult neurologists agreed (Faden et al. 1981:725-728).

As the surveys I already cited have shown, however, the differences between physicians and patients in expected levels of knowledge commonly are not resolved in the examining room. Physicians want specific kinds of information from their patients, and they have limited amounts of time in which to get it. Patients seem to have few skills to improve the extent of their control or communication in the clinical encounter. Thus what physicians call noncompliance in some instances can be seen as an expression of patient controls _after_ the clinical encounter.

Social factors clearly intrude into the examining room, for example the degree of understanding between people of different income and ethnic (or national) origin, sex, age, and/or education. Doctors and patients don't meet "cleanly" in the medical encounter as people divorced from their background--they meet as individuals with very different training, needs, and expectations. These differences, combined with the suffering that precipitate the encounter in the first place, help create many barriers to communication and understanding.

Conclusions

There are now more than 4,000 articles on compliance written in English. The topic is popular for a number of reasons, including its recency, its conformity with the physician's perspective on patient behavior, and its function of venting clinician frustration at the same time that it explores how to modify patient behavior. The literature about compliance centers on the physician-patient relationship, and is fueled by health-related disciplines like anthropology, psychology, and sociology.

The major problem with the literature on compliance, even when it is called adherence instead, is that it proceeds from too many implicit assumptions about the proper roles of physicians and their patients. It is narrowly defined within the specific history of modern biomedicine, and appears to assume that all health-oriented specialists are biomedical personnel. The contemporary concern with patient compliance has its origins in the development of the profession of medicine, especially the advent of professional controls over medical technology and resources. Many of the attempts made to decrease patient compliance lead more directly to coercive practices than they do to empowerment and shared responsibility.

There are two alternatives to the normative view of patient compliance: one emphasizes doctor-patient interactions more than it does patient characteristics, and examines clinical encounters in terms of expectations, expressed desires, satisfaction, and the like. The second extends the boundaries of relevant variables beyond the confines of the doctor-patient relationship, looking at the larger context of what it means to be sick and look for relief, and examining the types of controls available to physicians and to patients.

The following chapter applies these alternative views to the case of managing epilepsy among Rochester residents. Referring again to the idea that there is a natural history of managing a chronic illness, noncompliance will be analyzed as a group of component behaviors that accompany the process of managing illness over time.

CHAPTER FOUR: EPILEPSY AND THERAPEUTICS

Introduction

This chapter applies the theoretical issues of Chapter Three to the care and behavior of people who have epilepsy. I begin with information about the variety of treatments for epilepsy that have been used through time, then discuss the implications of the present-day focus on pharmaceutical treatments for epilepsy. To better contextualize my data from Rochester I evaluate the research literature on compliance with treatments among people who have epilepsy.

This chapter uses medical record reviews and individual interviews to contrast the viewpoints of physicians and patients about how people manage therapeutic regimens over time. The Rochester interviews show that there are two important categories of medication behavior: changing the dosage for an extended period of time, though continuing to take some medication, and discontinuing the regimen completely. I discuss the distinct reasons that were given for each of these two categories of behavior, and describe other non-pharmaceutical remedies that people with epilepsy use to treat themselves.

A brief history of treatments used for epilepsy

The history of treatments for epilepsy corroborates Temkin's (1964) contention that people's faith in drugs preceded their faith in physicians. Epilepsy has been recognized and treated as a natural disease seated in the brain at least since the fourth century B.C., when the first known monograph on epilepsy, On the Sacred Disease, was written (Temkin 1971:5). Hippocrates, to whom authorship is attributed, urged that epilepsy be treated with diet and drugs rather than magical remedies. (Magical remedies relied on demonic influences, while Hippocratic medicine relied on naturalistic explanations.) Despite the Hippocratic injunctions, ancient Greek lay and specialist healers commonly used miraculous curatives such as human blood and bones, iron, mistletoe, peony root, camel's hair, and various animal's genitalia to treat epilepsy (Ibid.:22ff.); these treatments continued in use into the eighteenth century. Temkin points out (Ibid.:24) that while the general thrust of Hippocratic medicine was toward treating epilepsy as a natural rather than a divine disease, these magical therapies were also sometimes recommended by the practicing physicians of the Greek era. The therapies appeared to work because physicians noted those instances when their patients improved. Individual experiences were not analyzed by statistics or supplemented with multiple observations, but they still served as physicians' best criteria to judge therapeutic efficacy.

Greek physicians in the fourth and fifth centuries B.C. said that seizures could be prevented by avoiding offensive smells or tastes, and immobilizing extremities thought to give rise to seizures. Abstinence from food or drink was a form of treatment, as was drinking vinegar, wormwood, holding one's breath, and exercising (1971:67). The disease was thought to be contagious; to protect themselves people would spit in the presence of epileptics and refuse to share their dishes. During Galenic times (second century A.D.) purgings, bleedings, and a moderate diet were recommended. Many pharmacological substances were used: Temkin (1971:79-80) lists 45 of them, 18 substances related to the prevailing understanding of how to treat the humoral pathology of the disease (e.g., cardamum, dried figs, whey, plantain, and mustard), 17 related to magical beliefs (hare's rennet, stomach and blood of the weasel, stork's dung), and the other 10 not specifically connected either to pathology or magic (e.g., fleabane, violet, frankincense, and sulphurwort).

Religious treatments of epilepsy competed with Galenic medicine in the Middle Ages. Beginning in the 16th century new drugs were used such as valerian and oxide of zinc, and both cold baths and vomitting were recommended. Supplicants with epilepsy also went on pilgrimages to monasteries, intoned the names of patron saints, and consumed healing plants. Healers emphasized drugs more than diet, but up until the eighteenth century the basic pharmacopeia remained much the same as it had been in Hippocratic times. Church lights, confession, prayer, and amulets often accompanied the use of drugs. Surgical procedures such as cauterization, trephination, cuppings, scarifications, and leeches were used through the nineteenth century. Masturbation was thought to be an important cause of epilepsy, and its cessation to bring a cure.

New remedies were introduced in the nineteenth century, and some were based on systematic comparative studies. Converts extolled the virtues of silver nitrate, turpentine, indigo, belladonna, and chloroform (Temkin 1971:293). Bromide of potassium was developed in the mid-nineteenth century, and was quite popular by the 1870s. Phenobarbital was introduced in 1912, and by the late 1920s had replaced the bromides as the most effective antiepileptic medication. Diphenylhydantoin (Dilantin) joined phenobarbital in 1937 as another effective anticonvulsant; neurologists now have more than 21 drugs available to control seizures, but these two drugs today are still the most widely prescribed anticonvulsants, and together form the primary treatment for epilepsy.

Epilepsy research and practice changed in 1956, when researchers developed techniques to measure serum levels of diphenylhydantoin.

Therapeutic levels of anticonvulsant drugs were established through trial and error, and these therapeutic ranges then became the yardstick against which individual blood levels were measured. "Noncompliance" among outpatients was discovered early, when users of the technique found that hospitalized patients whose medications were administered in increasing doses had a linear increase in blood levels of medication, while outpatients whose medications were prescribed in increasing doses did not (Buchthal et al. 1960). Physicians generally inferred that patients had non-therapeutic levels because they were "noncompliant," although non-therapeutic levels also result from prescribing inadequate dosages.

Measuring serum anticonvulsant levels has in the last 15 years become the preferred way to establish whether satisfactory levels of drugs are being metabolized. This therapeutic drug monitoring is likely to be done when a patient has had a weight change or an unexpected seizure, complained of side effects, been pregnant, started on a new drug or taken off an old, or had an annual neurology checkup. But this involves a dramatic change in doctor-patient relations: as the tools of diagnosis and treatment become more sophisticated physicians begin to rely more on their own tools and less on patient reports.

The advent of physiologic tests of medication levels brought a decoupling of patient self-report and physician knowledge about medication use: through their quantitative knowledge physicians could independently verify patient information, or even bypass patients' self-reports altogether. This meant a change in patient-doctor relations of enormous significance. A patient's own body now provided more accurate information about medication-related behavior than that patient's statements did: the body unwittingly yielded its secrets. Patients could be found out, tricked by their own body fluids, if they stated they had taken their medication when in fact they had not.

From the physician's perspective, successfully treating epilepsy today depends on precisely diagnosing the seizure type, selecting the proper drug type and dose, and monitoring the serum level of the drug to make sure that therapeutic effects are maximized and side effects minimized. This involves a certain degree of trial and error on the part of the physician, for many anticonvulsant drugs have a narrow window between therapeutic and toxic levels. For some patients complete seizure control can be obtained at low levels of one drug, for others only partial control can be obtained at high levels of multiple drugs. The recommended approach to anticonvulsant drug treatment today is to start with one drug only, in low doses, and maintain a dose until a stable serum level can be obtained. The physician then should increase the dose until the patient has seizure control or has intolerable side effects. If intolerable side effects precede adequate seizure control, a drug with a different chemical structure should be added. If the second drug is successful, the first one should be reduced or withdrawn. Many physicians still resort to multiple drugs to achieve satisfactory seizure control, but monotherapy is the recommended course wherever possible. This is because multiple drugs often interact, causing different therapeutic effects and side effects at different dosages. When therapeutic outcomes are hard to assess then it becomes more difficult to manage the course of treatment.

Literature on medical regimens and epilepsy

Tools in the form of serum drug monitoring became available in the mid-1950s, but research to understand and measure noncompliance with anticonvulsants was slow to begin. By 1965 there were only three studies of noncompliance among people with epilepsy. Such studies were more common by the 1980s: between 1965 and 1985 at least 17 were published. These studies as a group provide little unambiguous evidence that *any* variables are generally associated with noncompliance, though they do support the notion that demographic factors are not commonly associated with it. The many disparate findings must partly be attributed to the many differences in age, sex, diagnosis, referral source, and nationality of the populations surveyed, the definitions of compliance, and methods chosen to measure it. The scientific bias against publishing negative findings is a contributing factor to the disparate findings: few publications mention assessed variables which were not associated with compliance, thus one encounters many isolated positive associations and few negative ones.

The problem of attaining "therapeutic" levels and seizure control

Since the primary treatment of epilepsy is pharmacological, seizure control today largely comes from adequately prescribing and consuming anticonvulsants. While the medication consumption of a patient might be expected to vary somewhat if unsupervised, even closely supervised regimens do not necessarily result in serum levels of anticonvulsants thought to be adequate to control seizures. A Tennessee study of institutionalized patients not responsible for their own medications found 89% with non-therapeutic phenytoin levels among 38 patients, and 54% non-therapeutic phenobarbital levels among 24 patients (Wilson and Wilkinson 1974). This had to come from inadequate prescription or inadequate distribution of medications to the inpatients. Many non-therapeutic levels do come from patients' failure to take medication as prescribed, but detecting this is difficult even for physicians with access to the most advanced technologies available.

The ultimate problem for people taking anticonvulsants is that even closely supervised patients with therapeutic anticonvulsant levels are not guaranteed seizure control. A multicenter randomized clinical trial of four common anticonvulsant drugs, completed in 1985, found 39% of 421 participants had complete seizure control after 12 months of follow-up. The authors concluded: "Overall, the adequacy of seizure control in this group of patients given single-drug therapy was suboptimal even with expert neurologic care," and "the outcome of this project underscores the unsatisfactory status of antiepileptic therapy with the medications currently available" (Mattson et al. 1985:151).

The conclusions of these investigators had already been stated implicitly in earlier studies: both seizure control and recommended blood levels of anticonvulsants are difficult to attain. Although non-therapeutic levels of these drugs cannot be ascribed completely either to physician prescription or to patient consumption of anticonvulsants, it is startling to note the extent and range of non-therapeutic anticonvulsant levels and non-compliance by self-report in various studies, summarized in Table 4.1.

TABLE 4.1

Anticonvulsant Levels and Self-reported Noncompliance among Patients with Epilepsy

% Patients with non-therapeutic anticonvulsant drug levels	Total # of patients	Reference
75%	30	Dawson and Jamieson 1971
97	34	Rodin 1972
27	70	Sherwin et al. 1973
40	Not given	Eisler and Mattson 1975
28	65	Driessen and Hoppener 1977 (Netherlands)
32	50 (Clinic)	Mucklow and Dollery 1978 (England)
19	36 (Gen'l practice)	
26	153	Shope 1978
35	201	Shope 1980
50	30	Wannamaker et al. 1980
49	53	Peterson et al. 1984 (Australia)
19	252	Takaki et al. 1985 (Japan--children)

% Patients noncompliant by self-report	Total # of patients	Reference
36	87	Ferguson 1982
50	101	Peterson et al. 1982 (Australia)
42	80	Schneider and Conrad 1983
37	95	Stanaway et al. 1985 (New Zealand)

The problem of defining compliance in studies of epilepsy

Research on compliance in epilepsy suffers from the same limitations as the rest of the compliance literature. Compliance is a multifaceted behavioral variable that has been studied in many ways, making it problematic to compare studies. Studies of compliance among people with epilepsy have measured five distinct aspects of compliance: serum levels of anticonvulsants have assessed both (1) variation in consuming (or metabolizing) medications over time, and (2) absolute levels (whether therapeutic or not). (3) Self-reports of medication consumption were relied upon in some studies, while others counted (4) pills or container refill intervals, or (5) appointments missed. This variety of measures makes it difficult to generalize about "noncompliance" as a monolithic entity, especially when the same word is used to discuss phenomena as different as missing an appointment, discontinuing medications, and having a particular level of anticonvulsant medication circulating in the bloodstream.

The multitude of behaviors and physiological processes that can cause a serum level to vary or be consistently low, high, or therapeutic further complicate the use of the word "compliance", even when it is restricted to medication consumption. Medications can be prescribed incorrectly, or changes in body weight, metabolism, or concurrent medications can alter the rate at which medications are absorbed. They can be taken sporadically, or taken at consistently reduced or consistently increased dosages; discontinued abruptly, or tapered slowly. One of the causes of the conflicting evidence on variables associated with compliance is the fact that studies frequently do not measure the same dimensions of medication consumption. Shope et al. (1981) in a study of 163 adults from Minneapolis and St. Paul found that adequacy of dosage and consistency of medication intake over time had different correlates. Moreover 26 patients (16%) had excess levels of medication and appeared somewhat different from the others--Shope et al. proceeded to drop those taking more from the analysis entirely, reasoning that their hypotheses "were formulated expecting only under-compliance or adequate compliance."

Differences in measuring supposedly identical variables have been another cause of the conflicting evidence on compliance. Becker (1985) and Leventhal (1985) have pointed out that clinicians and social scientists may measure different aspects of compliance: clinicians may be most interested in determining whether enough medication is being taken to control the disorder, and therefore might label a patient "compliant" who consistently took 80% of the prescribed medication. Social scientists may be more interested in determining the links between level of compliance and level of perceived severity of some disease--they might use a continuous measure of compliance. To date there has been little overlap among the questions used in epilepsy studies to measure variables such as the level of seizure control or side effects, not to mention knowledge about the regimen or the disorder, simplicity of the regimen, or components of the Health Belief Model.

Many of the published associations between independent variables and compliance outcomes consist of a single positive report, sometimes joined by a negative. Since it make little sense to review such inconsistent findings, I will instead review those few studies which are well-designed and/or relevant to the population I studied. Often these studies showed the wisdom of measuring more than one dimension of noncompliance. Peterson et al. (1982) studied self-reports of missed doses, plasma levels, medication refill intervals, and appointments skipped among 101 adult Australian outpatients. They found that self-reported compliance was closely related to anticonvulsant plasma levels, refill frequency, and appointment keeping. Having more frequent and recent seizures was indirectly associated with self-reported compliance; seizure type, amount of worry about health, and perceived barriers to care were directly associated with self-reported compliance.

Shope, Ferguson, and others did a series of studies of adults in the Twin Cities region of Minnesota (Leppik et al. 1979, Shope et al. 1981, 1982, Ferguson 1982), which established that variation in dosage (whether there were many differences over time in the amount consumed) and adequacy of dosage (whether mean serum anticonvulsant levels were therapeutic or not) were separate dimensions of medication consumption. Ferguson's 1982 dissertation restudied 87 of the 177 people who had first been interviewed two years earlier--she found that while the means and variances of compliance measures were similar between the two study times, individual scores were not correlated. This means there was little consistency in behavior over time: over the two year followup period some compliers became noncompliers and vice versa. People who had larger variations in dosage levels over time had lower incomes and a larger number of seizures, perceived the regimen to be ineffective, and had past experience without medication. People who reported themselves as being noncompliant tended to hide their condition from others, lacked commitment to the regimen, and found it difficult to comply. Despite these correlations, a multivariate path model equation testing these variables showed that the combination of health beliefs and seizure status accounted for about 30% of the variance in the serum-based measure of compliance, and less than 20% of the variance in the self-reported measure of compliance.

Taking medications--evidence from the medical record

Keeping the conclusions of the preceding studies in mind, I wanted to study whether people changed their medication-taking over time, how they described their own medication and health service use, and whether the variables associated with compliance in earlier studies also predicted compliance in this one. Two research strategies helped to achieve these objectives: abstracting medical records, and interviewing people with epilepsy. This section discusses the results of the medical record abstracts, while the next two discuss the interviews.

To study changes in medication use over time I abstracted notations mentioning medication-related behavior in the study participants' medical records, and most recent serum levels of anticonvulsants. Many factors influence the total possible number of notations in the medical record mentioning medication-related behavior: the frequency of medical visits, predilictions of individual clinicians for exploring or documenting different strategies of medication use, frequency and variety of the self-regulation activities themselves. For these reasons medical records cannot provide an accurate summary total of self-regulation activities, but they can provide rough estimates of the variety of kinds of activities, the relative number of notes in the record, and their changes over time. In addition they can serve as a documented--though admittedly incomplete--history of medication consumption against which to compare interviewee self-reports.

Self-regulation documented in the medical records

The medical record is a multi-functional document: it summarizes aspects of the medical and social history of a patient; documents the work performed by various health care professionals; disseminates information about a patient to others involved in his or her care; presents a legal record of work performed or actions recommended; and justifies the fees charged for a particular medical action. The medical record can contain intimate details about a person's life, yet it commonly is never seen by the patient. As the property of the physician, hospital, or clinic, it represents that part of the patient's history that is available at any time to the medical staff.

Physician notes are the most important and most complex part of the medical record: through their notes physicians transform patient self-reports into clinical histories, combine and interpret the results of different physiological tests, speculate on reasons for treatment failure, predict outcomes of current treatments and plan new ones, contradict or question patient's accounts of treatment, and warn other potential caretakers of a patient's potential medical, psychological, and social problems. Sometimes physicians carefully describe patient behavior that differs from what they recommend, while other times they label it as aberrant and dismiss it. If a physician receives conflicting reports from sources as various as a patient himself, a patient's family or household members, laboratory reports, and clinical observations, the medical record is likely to contain a number of conflicting pieces of data. Sometimes physicians openly assess this data in the record, leaving evidence of their decision-making process behind them; other times they leap from data to a suggested regimen. The following excerpt from a patient's record does describe how the physician arrived at his decision. It also shows the delicate assessment this process requires: a patient's desire to appear compliant often can lead to attempts to influence test results, while the doctor's desire to get some "objective" evidence about the patient's usual consumption of medicines can cause him or her to try to catch the patient by surprise.

> When he came in (knowing beforehand that his blood would be checked) his blood levels were relatively high with Tegretol 12.0 mcg/ml and Dilantin 2.8... eleven days later when his blood was drawn without his realizing beforehand that it was to be drawn, his levels were Tegretol 1.5 and Dilantin 2.8. Clearly the difficulty in controlling this patient's seizures is almost totally explained by his erratic taking of medication.

The physician's job is to decide what source or combination of sources of information to believe, and to design, recommend, and assess the results of a treatment plan that will respond to what the physician has decided to label the clinical facts. But this process is filled with ambiguity for physician and patient: some patients may be anxious to follow a physician's instructions exactly; others may consider a physician's prescriptions to be just one of many possible treatment regimens to follow. Some color their symptoms to help the physician arrive at the diagnosis they have already selected for themselves. Disparities between the accounts of patients and their families can result from either, or both, side's errors. Medicine's public image is that of an exacting and rigorous business whose currency is facts. But physicians have no true "gold standard" against which to assess the various personal accounts and lab results they collect. Many rare but still possible factors can cause laboratory tests to give inaccurate results: tests can be done wrong; or samples can be switched inadvertently. Levels may vary depending on the interval between the drug ingestion and the measurement (though this is commonly standardized at Mayo Clinic), time since dosage change, the synergistic effects of taking multiple types of anticonvulsants, other comedications, recent weight changes, pregnancy, age, sex, concurrent illness or drug formulation (Johannessen 1981). Test results therefore can show non-therapeutic medication levels despite consumption as directed. All these can increase the level of uncertainty in the physician-patient relationship.

Many factors also influence the recency and value of the serum anticonvulsant level: persons having clinical problems such as frequent seizures, medication side effects, or signs of toxicity, are more likely to have their serum levels measured, as are persons who have had unexpected seizures. On average persons with more clinic visits related to seizures will have more levels recorded in their charts. These various influences can be subsumed under factors related to physician prescription (interval, dose, comedication, drug formulation), patient behavior (medication consumption, weight change) and patient physiology (pregnancy, rate of metabolism, concurrent illness, age, sex), though physiology will account for only a small proportion of the variation in serum level.

To measure patients' medication use as described in the medical record required that we scan the outcomes of all doctor-patient interactions: emergency room visits, hospitalizations, outpatient clinic consultations, phone calls, correspondence. If a single incident was described by more than one of these sources, we were careful to count and abstract only the first note for each incident. Records were reviewed back to 1975, the earliest time at which a patient could have discontinued medications and still been included as a prevalence case in 1980. We looked for, counted, and abstracted notes that mentioned behaviors differing from the prevailing clinical prescription. These notes often were based on patient self-reports, but since they described actions that were not likely to be approved by physicians there is no reason to disbelieve them. They included mentions of drug overdoses, comments by patients that they had forgotten, stopped, increased, or decreased their medication dosage, comments by physicians that they thought a patient was noncompliant, and notes in patient workups describing dosages differing from those prescribed at the time. Inconclusive notes were not counted, such as those where a physician wrote "I suspect patient A. is being noncompliant," but no corroborating evidence was presented. Table 4.2 gives examples of notes that were abstracted: Example One was coded as sporadic consumption, Example Two as a reduced dosage for more than two weeks, and Example Three as discontinued.

TABLE 4.2
TYPES OF NONCOMPLIANCE NOTES

Example 1:	"Rx phenobarb 30 mg. mostly 3x daily (occasionally takes 4/day when he feels jittery."
Example 2:	"In last 6 months he reduced Tegretol to 200 am and 200 pm q12 [every 12 hours], omitting noon 100 dose."
Example 3:	"Has <u>not</u> taken anticonvulsants for 2 years! Took them only for a couple of months in 1977 and then stopped. 'Thought it was alright to stop.'"

The records contained many entries documenting behavior at variance with the clinical prescription. Only 39% percent of the 199 medical records contained no mention of such behavior since 1975. There were 251 of these notes in all, with a range from zero to thirteen per record. Thirty-three percent of the records contained one note, 24% contained two or three notes, and five percent contained four or more. Categorizing the notes as a whole, 31% described low, inconsistent, or missed doses while 16% described long-term lower and 12% higher consumption than prescribed. Seven percent of the notes described anticonvulsant overdoses, 27% described discontinuing one or all medications, and six percent described taking no medications for more than three days and less than two weeks. Categorized by the self-regulation definitions of Schneider and Conrad (1983), 74% of the notes described incidents where people had taken no medication for more than three days, had changed the dose for more than two weeks at a time, or had discontinued their medication without a doctor's suggestion. This describes all the notes taken together, not the individuals about whom the notes were written--it implies that behaviors at greatest variance from the physician's prescriptions are those most likely to be noticed by (or mentioned to) physicians, and then deemed appropriate to enter into the medical record.

Categorizing these notes for each person (see Table 4.3), 28% of 1980 prevalence cases aged 18 to 59 in 1985 had discontinued medications since 1975 without a doctor's order, 14% had changed doses themselves for more than two weeks at a time, and 18% had varied their dose in other ways (overdoses, taking medication only as needed, other kinds of sporadic consumption). Measured by the conservative method of counting notes in the clinical record, 42% of prevalence cases had self-regulated their medications within a period of five to ten years. (This does not include one other strategy that Schneider and Conrad mentioned, namely altering medication consumption regularly under specific circumstances, for this was too hard to measure in the record.) This has to be an underestimate of the proportion of people who have self-regulated their medications, since it considers only a five to ten year period, and counts only those incidents mentioned to, or noticed by, physicians, and then entered into the medical record. Even though this is an undercount it nonetheless documents that a sizeable proportion of people with epilepsy have at one time or another changed the regimen their physicians have suggested.

TABLE 4.3
Notes in the Medical Record
Describing Medication-Related Behavior

Category	Percent of 199 records
Discontinued medications	28%
Changed dosage for more than 2 weeks	14
Other (sporadic, overdose, "noncompliant")	18
Total containing notes	60

Before exploring the types of patient and physician behaviors the notes describe, it is important to point out that the notes reveal ambiguities and potential conflicts between patients and physicians. An important ambiguity for physicians is inherent in their primary goals within the clinical encounter: they want to establish a diagnosis and recommend a treatment, but they face ambiguity in sorting out the different sources of medical information. An example of this follows.

(Note: Here and elsewhere changes have been made in some details of quotes or record abstracts in order to keep patient and physician identities confidential.)

> Note no phenobarbitol on last check! Discussed with patient and wife together today. He says he takes prescriptions regularly, she leaves it out but never sees him take it (usually asleep). He was confused again on dose and need for prescription.

To paint a coherent picture of patient behavior requires using many information sources, but this note describes sources that clash. Phenobarbital levels in the blood take about two to four days to drop 50% after consumption is completely stopped, so a physiological test report of zero suggests that no medication was taken for an extended period. The patient says he is taking it regularly, but the doctor thinks the patient is confused about the proper dose. The wife says she doesn't see her spouse take it, but she's usually asleep by the time he would. In this case the physician reinforces the need to continue taking the medication as prescribed, without appearing to affirm any of the competing sources of information.

Reinforcing the need to take medications as directed is only one possible response--physicians can also legitimate the patient's chosen strategy, rationalizing either that it is better for the patient, or that further dosage changes would be ignored anyway. There can be real social costs to questioning the veracity of a patient's reports about his own health or actions. Physicians can cause conflict by saying or implying that an anticonvulsant blood level of zero contradicts a patient's report of proper medication consumption. They rationalize, correctly or not, that the conflict itself may be less helpful for the patient in the long run than silently increasing a dosage, reducing a regimen's complexity, going along with the patient's choice, or teaching behavioral reinforcement techniques. Conflict may be managed most easily by a physician if it is avoided entirely, for patients can always go elsewhere if they perceive their physician to be more critical than helpful. The medical record sometimes portrays this delicate balancing between recommendation and rejection, as in the two following notes:

> He takes one Dilantin 100 mgm with 30 mgm of phenobarbital a day. [prescription was for two a day] He has never liked to take more medication because he claims it produces side effects. Would not change anticonvulsants at present. It is unlikely that he would take more medication even if we told him to.
>
> Patient states that episode (seizure) three months ago was due to not taking prescribed meds for several days prior to seizure. ...She will take her medicine as she wants to. She is not interested in facts--Mysoline SHOULD be taken in divided doses. Her medicines, (however taken) if taken have effectively protected her in the past. Since it doesn't make any difference what we say, no point in belaboring it.

When patients change doses or discontinue medications on their own, physicians can either legitimate or invalidate their patients' chosen courses of action. Among people with epilepsy the ultimate outcome depends on how well seizures are controlled: if a patient stops medication on her own, and her seizures do not recur, a physician may accept this as proof that the seizures have gone into remission, or may inform the patient that she is at increased risk of seizures. In either case he is unlikely to urge the patient to begin the medications again. If seizures do recur then a physician is likely to urge the patient to restart and continue to take medication.

These "tests" of continuing susceptibility to seizures usually are initiated by patients rather than physicians. They are good examples of what are called Type 1 and Type 2 errors in experimental designs. Type 1 errors are defined as the probability of observing a significant difference between two populations when in fact no difference exists; Type 2 errors are defined as the probability of observing no significant difference when in fact a difference does exist. Physicians assume that their pharmaceutical intervention makes a difference in seizure control and therefore should be continued, rather than assume it does not, and should be halted. They are likely to err on the side of "safety," committing Type I errors, defined in this case as urging patients to take medications even if the medications are "really" no longer necessary. Patients, on the other hand, are likely to err on the side of "risk," defined as stopping the medication. They are more likely to commit Type II errors, defined as assuming the medication has no effect on their condition, when in fact it does. Two different outcomes of patient's decision-making are seen in the two notes that follow:

> She stopped her phenobarbital one year ago with no seizures, "spells", etc. since. Says she has much more energy off phenobarbital and will continue off unless seizures recur. She recognizes increased risk of seizures.
>
> Patient called and stated that he had a seizure several days ago. He had stopped his medication. He stated he had been seizure free for years while on phenobarbital and mysoline. I told him to restart the medication and continue it indefinitely.

By stopping their medications these people leave themselves open to Type II errors--the physician in the first case accepts the patient's discontinuing her medication, the physician in the second does not. While we do not have a complete record of the physician's decision-making process, the note still effectively describes the relevant data: the patient has been off medication already for a long period of time with no relapse; and the patient feels better without the medication, appears willing to return to the medication if seizures recur, and appears cognizant of the risks. The second physician appears to be influenced by the occurrence of the seizure: since it happened while the patient was off medication, getting back on the medication ought to stop the seizures. This implicitly ignores the fact that some people have seizures even while on medications: medication is unnecessary if a patient can go seizure-free for years without it, and not be bothered by the possibility of having infrequent seizures.

Factors in the clinic record associated with self-regulation notes

The last chapter emphasized that noncompliance is more closely related to factors in the doctor-patient interaction than it is to patient's demographic characteristics. But a medical record does not reliably describe interactions, and cannot be used as an accurate guide to the social context of health care. I therefore decided to examine those factors that the medical record does describe well--clinical aspects of diagnosis and treatment--in order to see whether people who had different kinds of notes appeared to be different in other ways. Unfortunately medical notes are weak measures of patients' behavior: sometimes they are produced during routine physicals or annual visits, for example, when a patient says she stopped taking medication six months earlier, or when a patient prescribed a high dose of medicine has no detectable anticonvulsants in his blood. Other times notes appear in the record because a patient's behavior has prompted a medical consultation, for example when overdosing leads to hospitalization, or stopping medications causes a seizure. These different reasons causing notes to appear themselves relate to, and potentially confound, the clinical measures available in the record. Variables like elapsed time between most recent follow-up and last seizure, number of notes, and number of epilepsy-related visits, may vary with type of note because of the differences in factors causing the activities themselves to be noted. These factors are less likely to influence measures like duration of medications and of epilepsy, and age at note. Given these problems the following analysis is more suggestive than definitive.

We separately coded each person's most recent notation as well as all the notations found in their clinical record since 1975. Seventy eight persons (39% of the total) had no notes in their record describing behavior deviating from the doctor's prescription, while 73 (37%) had their most recent note describing one of the behaviors we defined as self-regulation strategies, and 48 (24%) had notes not describing a self-regulation activity. Fifteen of the 48 whose most recent notes did not describe a self-regulation activity had had earlier notes describing such activities, that is, when defined as "ever self-regulating" rather than as "most recently self-regulating", the total number of people who had self-regulated increased from 73 to 88 (44%). Using analysis of variance tests, neither age nor elapsed time since first seizure, first epilepsy diagnosis, or first medication prescription differed significantly among the cases when they were categorized into three groups (no notes, self-regulation notes, non self-regulation notes) describing either someone's most recent note or all his notes since 1975.

There were some significant differences among the three groups. People whose records contained notes describing miscellaneous regimen changes had the shortest intervals between their most recent seizure, or most recent neurology test, and most recent followup (2.9 and 0.9 years respectively), as well as the highest mean number of neurology tests in the five years preceding their most recent visit (8.0). This suggests that this group had been receiving the most intensive medical care, and had the poorest seizure control. The group with no notes had had the most years elapsed since a seizure or neurology visit (8.2 and 3.0 years), and the lowest mean number of appointments (4.4) in five years--see Table 4.4.

TABLE 4.4

Differences among Prevalence Cases Categorized by Most Recent Self-Regulation Notations

	Age	Epilepsy Duration	Seizure Duration	Years Since Last Seizure	Years Since Last Neurology Visit
Those without notes n=78	40.2	18.4	21.6	8.2	3.0
Those with non-self-reg. notes n=48	36.5	18.9	21.3	2.9*	0.9*
Those with self-reg.notes n=73	37.3	19.3	21.8	6.5	2.2
Overall N=199	38.2	18.9	21.6	6.3	2.2

* Significantly different from other groups by ANOVA ($p<.05$).

It appears that the people who were forgetting occasional doses of their medication, overdosing, or otherwise taking it inconsistently had had more seizures, more appointments, and more recent visits, while those who changed their medication more decisively were more like those who had always taken their medication as prescribed (or whose medication deviations, if any, had never come to the attention of their physicians). This may mean that sporadic changes in medication dosages initiated by patients were counter-productive in terms of seizure control, while the more deliberate changes defined as self-regulation were not. It may also reflect differences in the many other unmeasured factors that cause people to see physicians and thereby be "at risk" for having notes in their record: a higher incidence of other diseases, greater willingness to consult physicians, or higher underlying seizure frequency. Finally, these findings could be an artifact of the way I defined the category "epilepsy-related visit." It was difficult to categorize passing references to epilepsy during general check-ups, and impossible to count phone consultations accurately when we knew some physicians never mentioned them in the clinical record. I therefore counted reports from anticonvulsant drug levels, EEGs, or other neurological tests like CAT scans, that were readily and consistently available in the medical record. This was not the same as an accurate count of clinical visits, but it did provide a rough estimate of how intensive people's encounters with neurology had been, because multiple visits to neurology were unlikely to take place without accompanying tests. However, it does bias the record toward counting those visits prompted by difficulties like seizures or medication dosage adjustments.

Last epilepsy-related visit was counted either from most recent diagnostic mention of epilepsy, or from most recent drug level or test. Since diagnoses are coded at Mayo for each encounter with a physician, this would include those non-neurology visits where epilepsy was coded as a diagnostic category. Since neurology was not the primary source of care for epilepsy among all cases, this would still pick up some of those visits where, for example, epilepsy was discussed with internists, but the accuracy of the count depends on the diagnostic coding practices of particular physicians.

To examine these possible biases more carefully, the following table (Table 4.5) subdivides the main categories of notes into component categories.

TABLE 4.5
Differences in Clinical Outcomes by Types of Medication-Related Notes
(N=199)

Category of note	Years since last seizure	Years since last neurol. visit	# of visits in five years	# of Notes
No note (n=78)	8.2	3.0	4.4	--
NON SELF-REGULATION:				
ACD level, reported consumption, or label "noncompliant" (n=14)	3.6	1.5	7.6	1.7
Inconsistent doses (n=25)	3.1	0.6	5.9	2.6
Overdose or taking extra (n=9)	1.4	0.7	14.6	3.1
SELF-REGULATION:				
Changed dose for two or more weeks (n=29)	4.9	1.1	7.4	1.8
Discontinued (n=44)	7.5	2.9	5.5	1.8

Stratifying the results this way makes it seem that the nine people in the overdose group are making the non self-regulation note group appear to have had fewer years since their last seizure and neurology visit, more appointments in the five years preceding the last visit, and more notes in the record describing patient-initiated changes in prescriptions. As in the study by Shope et al. (1981), those who consume extra medication appear to be a separate group. However, eliminating the overdose group from the non self-regulation note group, the three groups (no note, non self-regulating, and self-regulating) would still have different means for years since last seizure and neurology visit.

Summary

The medical record is a multi-purpose tool for clinicians; as with many tools it shows signs of use. What physicians write about their patients sometimes says as much about themselves as about the patient. Clinical notes reveal what information is perceived to be important in reaching a clinical judgment about a regimen, and show how regimens get transformed over time. They document how conflicting information is resolved into a coherent story, satisfying at least for the clinical moment.

The medical records of these 199 people with epilepsy showed that almost two thirds contained notes describing uses of medication that had not been sanctioned by physicians. More than a third (42%) contained notes describing what, following Schneider and Conrad (1983), I am calling self-regulation of medications. Physician responses to self-regulation included legitimizing it or invalidating it. Both patients and physicians commonly test the efficacy of the regimen over time: patients use seizures as their guide, while physicians use seizures, medication levels, neurologic exams, and other technological tools.

Bivariate tests showed that age and duration of epilepsy were not associated with medication-related notes. People who did not have any medication-related notes in their record had had their last seizure longest ago, and had had fewer neurology tests in the five years preceding their last neurology visit. People with self-regulation notes appeared most like people without notes, suggesting self-regulation may not be associated with management problems like frequent seizures or clinic visits.

Self-regulation documented through personal interviews

So far I have been three steps removed from patient behavior: patients alter their behavior in the process of describing it to physicians; physicians interpret patient reports when they attend patients; and they again interpret patient reports when they decide how much of the interaction to record. One goal of this study was to assess the causes of self-regulation of medical regimens, and the relationships among the various forms of self-regulation (discontinuing, excessive, insufficient, or sporadic consumption of medication, non-attendance at clinic, or substitution of other regimens for biomedical ones). Information for these purposes came from personal interviews among adult Rochester residents with epilepsy, a source only once removed from the behavior itself.

Assessing self-reports

It is widely known that people may be unreliable when they report consuming medications according to prescription, while they usually are reliable when they report changing the prescribed regimen (Sackett 1978, and eight studies cited in Becker 1985). I used self-reports of medication use for many reasons. Few studies have found self-reported noncompliance to be inaccurate, though many have found self-reported compliance to be inaccurate; self-reports can be made more accurate by looking at specific aspects of taking medications rather than general estimates; I wanted to compare people's accounts with what I found in their medical records; and measuring serum levels might have increased the rate of refusals.

There were two final reasons for relying on self-reported information. I wanted to ask about a number of different dimensions of self-regulation, and these were unlikely to be elicited through any other form of research. Second, I wanted to know how people described their own use of medications and health services. Asking them was the best way to find this out.

One way to assess the validity of the interviews is to compare them with what was in the medical record. The two sources will not match perfectly, since it is reasonable to assume that some people told interviewers about incidents they did not mention to their physicians, and vice versa. In addition, the notes were abstracted only since 1975, while no time limit was set on the self-reports (except for a question about consumption in the past week). Despite these caveats, if the medical record--which often records patients self-reports--and interview self-reports measure the same behavior, the two sources should agree more often than they disagree. Table 4.6 shows that there is significant agreement between the two sources. In 53% of the cases interview and record agree, while in 27% they disagree, and 20% are equivocal. Both non-matching and equivocal comparisons were evenly split between record and self-report. Comparisons were called equivocal for those people who had notes that described occasional forgotten doses, or behaviors not readily classifiable as self-regulating, for example, a physician reporting "non-compliance" based on low medication levels without indicating whether, or for how long, a dosage was changed.

TABLE 4.6
Comparing Reports of Self-Regulation
in Medical Records and Interviews

Medication-related notes?	Past self-regulation mentioned at interview?			
	No	(% of 123)	Yes	(% of 123)
No note	25	(20%)	17	(14%)
Note(s), but not self-regulation	12	(10%)	12	(10%)
Self-regulation note(s)	16	(13%)	41	(33%)
(Don't know= 4)	X^2 $p < .006$			

Table 4.3 showed that 42% of the entire prevalence group aged 18 to 59 in 1980 had notations in their medical charts stating they had self-regulated their medications at some point since 1975. In contrast, Table

4.6 shows that 57% of 123 interviewees said they had self-regulated their medications (changed the dosage for more than two weeks, stopped for three or more days, and/or stopped completely) at some point either now or in the past. Adding the 16 respondents identified in medical records as having self-regulated who did not say so during the interview, 70% of the interviewees had self-regulated their medications.

Retrospective estimates of self-regulation approaching 70% are getting so large as to be immune to some kinds of analysis--after all, if everyone has self-regulated at some time, past sitational causes must be far more important than present demographic ones. Yet interview-based studies commonly explain past and future actions using present explanations. I chose to inquire about past and present medication consumption to get a rough sense for whether it appeared common over time, and what appeared to correlate with it in the present. To aid recall, separate questions inquired about changing dosages and completely stopping medications in the past, as well as changing medications in the present. Table 4.7 summarizes the responses to these three questions.

TABLE 4.7
Medication Use Reported at Interview

		Percent of 127
Q. 1	Changing dose:	
	Never	21%
	Yes, less than 2 weeks	43
	Yes, more than 2 weeks	33 *
	Don't know	2
Q. 2	Discontinuing:	
	Never	57%
	Yes, 3 days or more but began again	28 *
	Yes, discontinued completely	15 *
Q. 3	Dosage in last week:	
	Taking as prescribed	80% (of 99)
	Not taking as prescribed	20 *

(* = Behavior defined as self-regulation.)

Twenty-one percent of 127 respondents said they had never changed their dosage in any way from what was prescribed; 43% said they had changed it for less than two weeks at a time; and 33% said they had changed it for more than two weeks at a time. In a separate question 54 people (43%) said they had stopped taking their medication for three or more days at a time, and about a third (19) of these had stopped their medication altogether. Eighteen of the 19 people who had stopped completely were still off medications at the time the interview was done. Considering the answers to both these questions together, 57% of those interviewed said they had self-regulated their medications at some point. In contrast, when asked about taking medication in the week before the interview, 80% of the 99 people taking medication said they had taken the dosage as prescribed, while 20% said they had not. If we include those who discontinued on their own, then 39 of 118 or 33% were not taking medications as prescribed in the week before the interview.

It could be argued that our respondents misunderstood our questions, and anwered yes to our question about changing medications even if what they had done was to stop their medications. While this would inflate estimates of changing dosages, it does not appear to have happened. Some people who had discontinued their medications also had altered their dosage, for example some reduced their dosages for more than two weeks before finally stopping their medications completely. But in fact most of these people had changed dosages for periods of six months to three years before stopping, moreover they gave different reasons for changing dosage versus stopping: those who changed doses cited side effects as their most common reason for doing so, while those who stopped said most commonly that they wanted to see if they still had epilepsy. More than half of those who had changed the dose for any period of time said they had done it because they had forgotten, while less than 3% of those who had stopped for three or more days said they had forgotten.

Using anticonvulsants: common issues

There are many common issues for anyone who consciously changes a physician's prescribed regimen, but it appears that stopping medication completely versus taking it at increased or reduced levels are distinct rather than overlapping categories of behavior. I will explore them separately, after describing some of the basic concerns.

Managing epilepsy involves many ongoing evaluations (testing), the outcomes of which can change as one ages, changes jobs, has a longer interval since the last seizure, or develops a different feeling about the likelihood or effects of further seizures. The following quote shows how one middle-aged woman described her testing process:

> #119 [Case number--these are used consistently for all quotes.]
>
> On my own I decided to decrease my dosage by half. I figured if the seizures are in my sleep who am I gonna hurt anyhow? You weigh one value against another: is it worth feeling protected from seizures to feel like THIS every day? It was more of a handicap walkin' around drugged up than having a seizure while sleeping. If my seizures had been in the daytime I'm sure I would have taken it more seriously.
>
> I decided I would try on my own to stop and see if I had them. How will I ever know I can handle it if I don't quit the meds and give it a try? I didn't tell the Clinic doctors because they'd just tell me to keep on. If I had another seizure it wouldn't cause a handicap or nothin', it's not like stopping your heart medicine--not severe results like that from one seizure. I told the docs about it 6 months after I stopped, told 'em "I don't intend to go back on it." The Dr. said "If you're seizure free, I don't see why, either".

The testing process described in this woman's words involved 'weighing one value against another': how great a problem are a medication's side effects when compared to its main effects--the seizure protection the medication is supposed to convey? This woman felt that the nocturnal timing of her seizures reduced their potential liabilities. In addition, she saw the possible outcome of stopping anticonvulsant medication (having a seizure) as being only short term when compared to the long term outcome of stopping heart medicine (having a heart attack and, presumably, dying or being disabled).

Another issue for the patient is assessing how a physician will react to the news that one has changed dosages without a prescription. In this case the interviewee expected to encounter a clinical bias toward staying on medications: she expected she would be told that she should go back onto medications, and she therefore delayed telling her doctor. When she did tell she met a different response than anticipated: if she was still seizure free her doctor did not think she should continue on the medications either. This was a vindication of her own judgment and decision. However, it is another example of the competing agendas of physicians and patients: this woman did not fear the occasional seizures that might result if she stopped her medications, and she had strong reactions to the side effects. She expected her physician, like the rest of "the Clinic doctors," to value seizure control over side effects, and to urge her to go back to the medications. She was surprised to find that he did not.

Evaluating the regimen: changing medication dosages

More than half of the 98 people who had changed the dose themselves said they had forgotten one or more doses. (I will deal separately with altering the dosage while continuing to take some part of it, and discontinuing medication entirely.) Table 4.8 shows that somewhat different reasons were given by those who had changed the dose for less than two weeks compared with those who had changed it for a longer period. Those who changed the dose for less than two weeks most often mentioned forgetting (59% of responses); other reasons included wanting more protection (12% of responses, primarily mentioned by people who were taking extra doses), disliking dependence on medications (7%), see what would happen (6%), medication side effects (5%), and that they were young and/or emotionally immature at the time (5%). These reasons were given by those who had missed only a few doses, or sporadically taken extra medication to prevent a seizure or reduce perceived precipitants of seizures like anxiety or other emotional pressures.

TABLE 4.8
Common reasons for Changing Medication Intake

CHANGING DOSE LESS THAN 2 WEEKS (N=56)

	# Responses	%
Forgot[1]	50	59
More protection	10	12
Dislike dependence	6	7
See what happens	5	6
Side effects	4	5
Emotional immaturity	4	5
Other	6	7
(Total responses)	85	100%

CHANGING DOSE MORE THAN 2 WEEKS (N=42)

	# Responses	%
Side effects	13	21
Feeling well	11	18
Dislike dependence	7	11
See what happens	6	10
Forgot	5	8
More protection	3	5
Save money	3	5
Other	14	23
(Total responses)	62	100%

[1] Forty of 45 people who took less medication for less than two weeks said they had forgotten it.

People most frequently said they had changed the dose for <u>more</u> than two weeks because they felt medication side effects (21% of 62 responses); others did so because they felt they were doing well (18%), disliked their dependence on the medications (11%), wanted to see what would happen (10%), forgot (8%), wanted to get more protection (5%) or save money (5%).

The major difference between omitting or increasing doses sporadically and changing a dose for a long period appeared to be that people changed for longer when they felt too many unpleasant side effects from the medication at the prescribed dose, or felt they were doing well and needed less medication than they had been prescribed. Seizure control may not be as important a goal to all patients as is living a life free from feelings of slowness, lassitude, or poor concentration.

People who altered their prescription dosages usually did it carefully, following their own regimen, rationalizing it, and setting their own limits for what they felt comfortable doing on their own. For example, some said that while they were willing to change dosages on their own, they were unwilling to stop consuming the medication altogether. This can be seen in the following statements by a middle-aged woman:

> #135
> I've had the same MD since 1961. I tried another one a year after a Minnesota Epilepsy League meeting, where they were talking about levels and stuff. My doctor had never given me a blood test, so I went to one who did--boy did I regret that. He upped the dose to six or seven a day, and I felt awful. That Dr. called me an incompetent patient: he kept saying there was no way I could be feeling way I was feeling about the medications if I was really an epileptic. We argued back and forth. He brought tears and that was that: I never went back to him.
>
> (Later in the interview:) I felt too many side effects from the higher dosage. I went to two [pills a day] for three years, then got curious myself and decided... "what would happen if I reduced it one more--how would I feel?" But I was really careful: took one less every other day, then down to one, and I felt "wow--this is great." I try not to forget the one--but if I forgot, I wouldn't double it. I can go a few days without having any petit mals. I think that's good, too, but I'm not that brave to try one every other day. I think if Dr. H. said to try, I would do it, but only if he said it was OK.

Similar care was taken by a 30 year-old nurse who had also reduced her dosage because of side effects. She also said she met scepticism from her physician, but continued on her reduced dosage nonetheless, supplementing it with non-biomedical therapy.

> #131
> He [MD] said 'you can have fun and test it' but he doesn't believe it will work. He knows I'm a nurse and knows I won't stop completely. I tapered slowly, and the seizures increased for a while then decreased again. I also do relaxation therapy to help and if I wasn't doing that would be on three a day now. I think they're really provoked by stress--mine are. I can't talk to anybody about it. My doctor doesn't understand. I'm doing it [taking less] because of the side effects--I think I'll lower the rate of side effects, but my Dr. says I'm not. He says I'm playing with my meds.

These women both indirectly attest to the importance of medical knowledge gained outside the doctor-patient relationship: the first learned from a consumer group that there were tests which might help her to assess her medication dosage more effectively. This information caused her to switch (to her subsequent regret) to a physician who would do such tests. The second felt that stress precipitated her seizures, and she therefore relied on a combination of relaxation therapy and a reduced dosage schedule. Both of these women encountered strong opposition from their physicians: one was called 'incompetent', the other told she was 'playing'. (Medical records from these women showed no signs of any conflict--the first had no notes describing any self-regulation, the second had two notes describing dosage reductions.) These epithets were the physicians' attempts to invalidate, or at least devalue, their patients' roles in monitoring and managing their own medication regimens. This backfired for the physician mentioned in the first excerpt, since rather than submitting to his regimen and the unpleasant side effects it caused, the woman continued to manage her own regimen by finding another physician.

Calling a patient 'incompetent' implies she is unable to take care of herself, and 'playing' with medications implies a childish or at least naive level of knowledge and responsibility. Yet these excerpts show that the women are exercising great care in their dosage changes: the first tapers her dose exactly as a physician would, though over a much longer period of time than a physician would recommend. She repeats the professional injunction that doses should not be made up if missed, and has chosen a minimum dosage below which she will not go without her doctor's permission. The second woman also has tapered her dosage slowly, and supplements her lower dose with the relaxation therapy that she considers an important part of her regimen. In each case the women feel their own strategy works: they are acting within their own rational strategies of self-management which resemble, though they do not duplicate, biomedical recommendations. They continue to seek medical care, but use their own ideas to modify the injunctions they find in the clinic. Having control over their illness and its treatment is more important to these women than whether they completely stop the seizures.

While dosages can be changed consistently and carefully, as the two previous women did, they can also be changed inconsistently through neglect, overt rebellion, or covert rebellion. A man in his mid-20s explained that he had taken medications sporadically for an extended period of time before finally refusing to take any more at all--his decision to stop was approved later by his physician.

> #148
> I got sick of taking pills every day of my life. I was a teenager, rebellious, wanted to be like everyone else. I don't take drugs, it's not my style--I don't even take aspirin. I'd take the medication every once in a while in front of my mom so she wouldn't catch on. Six months or a year later I went for my regular visit--told my doctor "I'm not taking them and I'm not going to." He said he'd take me officially off it. He would have kept me on it for life, I think...

The following explanation was offered by a female legal secretary in her late twenties:

> #132
> In High School I started skipping once in a while--I was on a higher dose in the evening anyway. In college I would not take 'em if I was out drinking--I'd leave out a pill or so. In the last five years I'd been skipping a lot, especially the afternoon dose, then in the last year even more. I was skipping some of 'em but getting caught on the tests--I was getting lazy, not even carrying it around. The timing was hard. I had a three pm dose that that was left over from when I was in elementary school--I blew off that dose. I took the evening dose 'cause I usually had the seizures at night. I'd take extra before going to see the Dr. to get my levels back up, but usually that didn't work. The last time my levels were way too high so my Dr. knew I'd done it again.
>
> Why? I just wanted to get off meds. I always had to come in on a vacation day. I had seizures so far apart it didn't seem necessary. My MD kept saying five years seizure free, but then I'd always have another just before the time was up.

This woman rebelled rather than developing her own consistent medication regimen. Taking her medication when she came home from school was convenient when she was a child, but it became an inconvenient interruption when she was older. She reasoned that her medication intake should match the time (evenings/nights) when she had had her past seizures, and felt that the increased evening dose might offer sufficient protection on its own. But these rationalizations carried less weight as time passed. The regimen's interference in her activities made it more onerous, and the seizures seemed less threatening. She attempted to hide her 'improper' behavior from her physician by taking extra medication before blood tests were drawn, but was betrayed by her own actions. Another factor in her lack of commitment to her prescription was the long interval her physician chose to signify seizure remission. She was unable to attain this interval, and judged it was too long. The clinical definition of when she should consider tapering was out of line with her personal definition, but this disparity did not lead to dialogue and compromise. It led instead to attempts to cover-up, attempts which probably resulted in larger swings in medication levels than would have occurred had she felt comfortable maintaining her reduced consumption and telling her physician about it.

The strategy of telling was adopted successfully by another woman (aged 37) who had changed her dosage, and who also explicitly viewed her actions as rebellious. It is possible that her age allowed her to have more confidence in her actions than the younger woman just described.

> #122
> When I took the prescribed dose I felt sluggish and tired. I don't wanna feel like a pill popper and a dopehead. Sometimes you need to fight back a little bit. When I went down [to the MD's office] I told him, he asked how I was doing and said as long as you've got control each day you go do it.

There appear to be some differences between the factors leading people to modify their dosage but continue the regimen, or discontinue medications. As we saw in excerpt #135 above, in which a middle-aged woman painstakingly reduced her own dosage, people may choose regimens that do not agree with what their physicians suggest, but they may follow their own modified regimen as faithfully as physicians would want them to follow their regimen. Similarly some people who were willing to change their medication dosage were quite unwilling to stop taking it completely. Asked if she had ever stopped taking her pills for more than three days at a time, the 37 year-old woman quoted above answered, "No--I'd be too afraid of what might happen. As long as I don't have the attacks and I'm on pills that's alright." She felt that she could cut down her dosage without danger: the reduced dose still gave her a sense of security that would disappear if she stopped completely.

Summary

People usually did not consult with their physicians about changing their dosages. They commonly explained their failure to consult by suggesting they had different priorities from their physicians. These different priorities ranged from the value attached to time (differences in perceptions of short term risks and long term benefits); to the significance attached to complete control of seizures (physicians appeared to be more tolerant of side effects if control could be obtained, while many patients valued clarity of thought over complete control of seizures). Some people hid their actions from their physicians because they thought their physicians would disapprove, others did so because they rebelled against the physician's authority, and still others openly acknowledged that they were following a different regimen. Physicians had varied reactions to their patient's behavior: one labelled his patient "incompetent," another said his patient was "playing" with medications, and others changed the prescribed regimen to suit the patient's behavior. Some people managed regimens of their own choosing as carefully and strictly as their physician could have hoped they would follow his.

Most important, factors outside the doctor-patient relationship commonly impinged upon it. Information was collected from other physicians and medical sources, as well as from non-medical sources. This information was used to measure the success of any particular clinical encounter, as well as the ongoing success of the relationship between clinician and patient. When relationships did not measure up, people switched doctors--a potent source of patient control over physician behavior.

Evaluating epilepsy: people who stopped taking their medications

The last excerpt came from a woman who was willing to change her medication dosage but was unwilling to stop it entirely. How did those who stopped taking their pills explain their action? Table 4.9 shows that the reasons most frequently given by the 54 people who stopped medication for three or more days were that they had been feeling well, disliked the dependence on medications, wanted to see if they still had epilepsy, acted young and immature, tried to save money, felt side effects, and ran out of medicine without repercussions. These reasons together accounted for almost 70% of responses.

TABLE 4.9
COMMON REASONS
GIVEN FOR STOPPING MEDICATIONS

STOPPING FOR 3+ DAYS
(N=54)

	# Responses	%
Feeling well	17	23
Dislike dependence on meds.	9	12
See if still have epilepsy	8	11
Young and immature	6	8
Save money	4	5
Side effects	4	5
Ran out of meds. w/o problem	4	5
Forgot	3	4
Relieve life pressure	2	3
MD didn't check up	2	3
Other	16	21
(Total responses)	75	100

(Note: Respondents could give more than one reason.)

The explanations given by people who had stopped their medications were somewhat different from those given by those who cut their dosage. While people who cut their dosage still trusted and relied upon the regimen as a whole, those who stopped their medications generally did not. A third of the people who stopped their medications mentioned "feeling well" or "seeing if I still had epilepsy" as their reason--these people were interested in learning whether the condition still existed, and whether any medication consumption was necessary. Those who continued to take the prescribed medication at reduced dosages primarily wanted to see whether they could reduce or stop their medication-related side effects. Discontinuing medications assesses empirically whether the condition still exists; changing the dose accepts that the condition still exists, but assesses whether the regimen can be improved.

Testing by patient and by physician is a pervasive part of managing epilepsy, and is likely to be equally important in other chronic episodic diseases such as asthma, diabetes, or schizophrenia. Physicians do all they can to discover the underlying cause of someone's seizures, but as we saw in Chapter One perhaps 75% of cases are idiopathic. Neurologists use the electroencephalogram (EEG) as the primary diagnostic tool for epilepsy. It measures abnormal brain function, the physiological cause of seizures, but it also can give inconclusive results. Estimates vary, but between 5 and 25% of people who have seizures have normal EEGs under routine recording procedures, and given intensive monitoring the range narrows to 5 to 10% (Hopkins and Scambler 1977). Specifically abnormal EEGs are found in 5 to 20% of the people free from seizures (Doose et al. 1972, Tsuboi and Endo 1977, Tsuboi and Okada 1985). Physicians act most definitively when they test whether the treatment they have chosen (most commonly, pharmacologic) is being administered correctly and absorbed in sufficient quantities. Yet as we have seen, this process of getting medication blood levels also is a process of some complexity and uncertainty.

Patients also test for the appropriate treatment and dosage, but they are more apt than physicians to continue testing for the existence of the disorder itself. Physicians rely on the EEG as a window into brain function. People with epilepsy, on the other hand, rely on their own behavior as a measure of brain function: for many, whether or not their EEG is abnormal is less significant than whether they continue to have seizures. Since epilepsy is an episodic disorder, it can be proven to exist only if additional seizures happen. The medication is supposed to stop the seizures, so only by stopping it can one see whether seizures are still possible. Physicians are more accustomed to viewing an abnormal EEG, or a history of seizures, as sufficient evidence for a propensity to more seizures--they need not see the seizures to know they still can happen. Even the definition of "health" can differ for physicians and people under treatment: physicians appear to define health as the complete absence of seizures, while at least some patients define their health as a <u>relative</u> absence of seizures. Excerpt #132 above showed the problems caused for one patient when she could never quite attain her physician's defined period of five years freedom from seizures. The following quote shows a similar assessment that the speaker's health is <u>relatively</u> good:

> #109 (male, age 22)
> If I had 'em [the pills] sitting out on the counter and I seen 'em I'd either take 'em or put 'em back up on the shelf. I suppose I feel they're pretty well under control now compared to what they used to be. I'm just not real good about taking medicines. I believe that's an excuse for me but I use it. Maybe I'm just praying tomorrow's the last day of 'em. I wait and see, and if they don't [happen] I think they're gone.

This interviewee had a more ambivalent attitude about taking medication: he feels his seizures are less frequent than they were before; therefore it is more difficult to justify taking the medications as prescribed. He can admit he is rationalizing his behavior ("that's an excuse"), but he cannot say he will stop the rationalizing ("but I use it"). Starting his next sentence with "Maybe" allows him to reveal his deeper motivations without appearing too committed to them. Taking medications reminds him that potential seizures still lurk in the future, while not taking them allows his hope to go forward unimpeded.

Just as not having seizures while off medication can allow a person with epilepsy to think the condition has disappeared, so having seizures while off medication can reinforce knowledge that the condition still exists. Sometimes having seizures after stopping medication brings more faithful following of clinical regimens, as illustrated in the two following quotations, the first from a man in his 30s, the second a man in his 40s:

> #112
> I flushed it down the toilet when I was about 18 or 19. How did I know they were working? I was spending $15 a month. I wanted to see, not just take the doctor's word. He was right. I went about one and a half weeks, then had a seizure.
>
> #117 [Had stopped once unsuccessfully when age 17.]
> In 1970 I wanted to see if I could do it again. I thought "it's been so long since you've had one [a seizure], you could just try stopping it [the medication]." A couple of weeks or a week and then I had a seizure. Then I knew I really had to stick with 'em.

Dependence: on medications and physicians

Another motivation for stopping medications is feeling that one depends on them. For many a fear of dependence includes a fear of physical or psychological addiction to the medication, but fear of dependence can also spring from what that dependence signifies: healthy "normal" people need make no extra effort to remain that way, while people dependent on medications have to take substances to maintain their health. This need to be like the rest of one's peers is particularly acute during childhood and adolescence, as illustrated in the next quotation.

> #144 (Female, age 36)
> [ever stop?] Yeah--I wanted to be like the other kids and go without medicine. I was 11 or 12, had a grand mal seizure after about a month or so without medicine. Never again, my parents vowed...they monitored me until I got away from them. Medicine meant I was different.

The relationship between doctor and patient was a factor in stopping as well as changing dosages. While it was not a common response, two people mentioned a lack of physician or clinical follow-up as a reason they stopped taking the medications. These people suggested in effect that if their physicians did not care enough about their medications to assess their progress, they certainly were not going to keep taking the pills. They did not feel responsible for following their doctor's orders if their doctor did not show continuing interest and concern. They also labelled the medical profession arrogant, for they felt their physicians believed that once pills had been prescribed the problem disappeared and no follow-up was warranted. This rationalization went: "Well, if you don't care enough about this [complicated, expensive, side-effect ridden treatment] to check up on whether it's working, I certainly can't be expected to care about it either." The first statement comes from a female nurse in her mid-30s, the second from a male salesman in his mid-40s.

> #206
> Sometimes I forgot--that's easy to do when you're on [meds] for a long time. The medication was really irritating me--I felt more sluggish on Dilantin. Just didn't think that I had seizures. Finally, after times of forgetting, or cutting down on purpose, I just stopped taking Dilantin. No-one seemed to be checking up on the amounts. I'd be really upset with a patient who did what I did.
>
> Nobody checked to see how long I was on Dilantin. Do you go back to the Doctor to see about it, unless you're having problems? I think they completely forgot about me once they put me on meds. "Well, that cured her."

> #213
> At the Clinic they don't know or have a 'tickler' file if you don't come back. After the blood test I stopped medications. Didn't ask my Dr., just cut off my medications. I never got the blood test results, got no letter, nobody called. I expected after the blood test to be told if I was OK--never heard. They dropped the ball then.

These two respondents have what might be called a "personal" approach to their ongoing medical care: they respond to a physician's requests as long as she plays an active role in their care, but if they think a physician has lost interest, or has decided without proof that the chosen treatment is working, they reject the treatment.

Assessing risk

In contrast to the "personal" approach of the two interviewees just quoted, other respondents had a more "objective" approach to their medical care. The next interviewee, a 28 year-old woman, explained her behavior using a vocabulary of competing assessments of risk factors.

> #103
> When it was first diagnosed I was in my first year of college. I went to the Emergency Room then, still semi-conscious. They said "You have epilepsy," but there was nothing physical there. I was totally confused as to why I was so weak. They said "Here: take these the rest of your life." I felt after a couple of years no physical effects, nothing I could put my finger on. I didn't feel anything different. Finally I started getting lax, I was worried about side effects--I could put my finger on that, but not on the seizures.
>
> [She discontinued her medications for about a year, then had a seizure and went back onto the medications, then got pregnant and stopped the medications a second time.]
>
> The second time I stopped my medicine I was worried about the nature of the risk factors--NOT the level of the risk. It could have been .0001 but still too severe. No matter how small it was still a confirmed risk, against the likelihood of having a seizure which had been so long ago. [She started her medications again after delivering her baby.]

These respondents continually evaluated the quality of their medical care in terms of the quality of their social life. Sometimes patients and doctors agreed in their assessments, other times they did not. There were differences in knowledge and perception of risk: patients such as the woman just quoted evaluated side effects as known negatives, while protection from seizures which had not happened in years was a dubious positive. This particular respondent also articulated her own separation between (and different value of) the <u>nature</u> of a risk when compared to its <u>probability</u>. The possible outcome (congenital abnormalities) was so threatening that it overwhelmed the low probability of its occurrence. A physician, accustomed to working with probabilities, would be likely to interpret a risk of .0001 as quite low, and worth the gamble given the seizure protection the medication afforded. But this interviewee interpreted the scientific meaning of risk, the probability that an event will occur, in a different way: in her view, even a very low level of risk (".0001") still meant that there was a "confirmed" chance that the event would occur to her. This event was much more threatening than a seizure, and justified not taking the medication during a pregnancy.

This is not an isolated instance. Studies have found differences between 'scientific' and 'lay' conceptions and worries about risk and low probability events (Douglas and Wildavsky 1983, Fischoff et al. 1979, Gifford 1986). The public weights low probability events with devastating outcomes more negatively than scientists do. The public also weights low probability events with positive outcomes (lotteries and the like) more positively than scientists do. Epidemiologic or clinical statements of risk get reinterpreted by patients according to their own values. These reinterpretations are another factor in behavior that differs from what clinicians expect or recommend.

The magic of medicines

In deciding whether to take medications as prescribed, people evaluate their perceived physical costs (side effects, seizures), social costs (dependence, disclosure, financial), and emotional costs (anxiety, fear). The following quotation is from an interview with a 55 year-old man who in the past had cut his dosage for extended periods of time, and stopped his medication entirely for as long as three weeks.

> #126
> I changed it cause I didn't have money to buy them. I wanted them to last as long as I could. If I took even one a day I didn't feel I'd get a spell. As long as you take SOME--better to take it all, but if you can't afford it, you make sure you get SOME in your brain. Sure they want you to take it all, but if you ain't got it where you gonna get it?

Decisions to self-regulate medications also depend on evaluating the effectiveness of the substance itself. This man's faith in his medications caused him to take at least some medication for as long as he could stretch it out--he had an almost magical belief in the power of his medicine, since even taking one a day, a physiologically sub-therapeutic dose, made him feel protected from seizures.

Though it is contradictory at first glance, having little faith in medications can cause one to take extra medications or stop taking them entirely. This depends in part on how much the medications seem to help: if medications are only somewhat helpful, then taking more than the prescribed dosage will be necessary to get a desired level of protection. On the other hand, if medications are not too helpful at all one may eventually decide to stop taking them altogether. The congeniality of these ideas was shown by a middle-aged woman who had taken extra medication at some times, and discontinued it at other times.

> #118
> When I got lots of headaches I'd take more meds--I didn't have a lot of faith in that Dilantin--so much [information] was kept from me. They must have said "just give her pills so her parents will take her away". I was living in a small town, had no access to books and information. No means even to read on it.
>
> [Why did you stop?] I never really believed the Dilantin was helping--I didn't have faith in it. I stopped on my own in '78: my sister, a nurse, got really angry and told me I needed to go through some program at Mayo to reduce it, but I didn't. I just did it on my own.
>
> [Ever have a seizure while on medication?] Yes, and then I would lose trust in it--maybe stop for a while. And reading studies about diabetics running their own sugars and doing it wrong and losing limbs and stuff. The medicine does weird things to you. The neurosurgeons are condescending: you say "I'm taking what you tell me even though it's not helping", and they look down at you. They can't understand why you wouldn't take the medications.

Where does one acquire faith in a medication? This woman felt she had few resources to obtain medical information, and never acquired any external support for believing that her medication was powerful. Yet she also could draw on few personal or physiological "internal" experiences of the medication's efficacy: she had seizures even while taking it correctly, was worried about the "weird things" it could do to her, and felt she needed more of it when she had headaches. Stories of improper self-care by people with diabetes filled this woman with fear, made her feel less like taking sole responsibility for her care, and probably helped justify her inaction. But when she shared this feeling with her neurosurgeons, telling them she was doing what they asked even though it did not seem to help, she met incomprehension rather than understanding. This again points out that social context is important in managing medication regimens: this woman articulated her needs for information, as well as satisfaction with her sources of medical care.

Following the regimen

Given the relatively high proportion of people who said they had forgotten doses, changed the dosage on their own for a long period of time, or stopped on their own, it is instructive to look at some of the reasons given by the 21% of respondents who said they never had changed their medications without a doctor's orders. Often these people said they were afraid of having another seizure, even though in some cases (e.g., #108) the most recent seizure had been as long as 18 years ago.

Some of these people were so committed to the idea of taking medications that they had stopped going to physicians who suggested they try decreasing their dosages. For example, a 40 year-old man said:

> #108
> My MD gave me a prescription that lasted for years. He retired and I had to go back. If I didn't have to go back I wouldn't have. It's a pain in the neck for me to see the doctors. I lost confidence in the next doctor I saw there: he said "Why don't you reduce the dosage and see what happens?" Now I go to a different clinic. I think the risk of having a seizure and losing my driver's license isn't worth it. It isn't worth it to fool around.

This is a case where faith in drugs exceeds faith in physicians. Physicians commonly experiment with dosages and medication types for some time before establishing a regimen. This may be viewed by patients as an essential part of managing their illness, one which they themselves will use--as we saw earlier--to find the best regimen. It is congruent with this empirical method to suggest that a patient with no seizures in 20 years might try taking less or no medication, but it reveals that establishing, maintaining, and discontinuing a regimen requires a good deal of trial and error during each phase. It further potentially exposes a patient to the loss of a routine habit, one which in some cases has become rationalized as a necessary prophylactic. Finally, this patient thought it could cause him to lose his driver's license--from his perspective his physician was being cavalier with his livelihood, and that was grounds for his dismissal. (Ironically, Minnesota state law excludes seizures resulting from physician-initiated dosage changes from the list of reasons for drivers license suspension.)

I said before that physicians are biased toward maintaining medication regimens once they are established, unless or until side effects develop or a patient objects. By sharing his uncertainty about proper dosage with a patient, a physician leaves himself open to criticism and loss of face; he is admitting he has no infallible solution, and that in fact the patient may be as well equipped to explore the issue as he. This may facilitate patient-doctor communication for some patients, but it can frighten away those who, like the man just quoted, feel that their physician does or should know more about their care than they do.

Leaving a physician who suggests tapering a dose is probably not a common reaction. More common is disagreeing, and urging a physician to continue the familiar regimen. A 35 year-old woman explained why she had never considered stopping her medication:

> #252
> My Dr. suggested stopping, but I feel better taking 'em--if I was taken off medications I'd fear I was gonna have one. If I'm taking 'em, I don't worry. I told my girlfriend "I may take them the rest of my life, but at least I don't worry about having seizures".

Other sources of care and treatment

In the last chapter I articulated the need to examine self-care and self-medication as processes relevant to compliance, and I presented research data suggesting that these were common actions among the U.S. population. I found during interviews that these were also common in

Rochester. Again these estimates probably underestimate the prevalence of these activities, since the pervasive influence of the Mayo Clinic is likely to reduce the acceptance of self-medication in the local population.

I asked interviewees whether they had any medications in the house that were leftovers from other prescriptions. Forty seven of 127, or 37%, said they did. People who said they had leftover medications were better educated ($p<.01$) and had higher incomes ($p<.02$) than people who did not. They did not differ by age or sex. People with leftover prescriptions were also far more likely to have changed their dosage of anticonvulsants for more than two weeks ($p<.001$), but were no more likely to have stopped medications, than people who did not have leftover prescriptions. This probably means that the leftover prescription medicine in the house was that which accumulated when dosages were reduced by interviewees, though it does not explain why people who stopped taking their medication did not also have leftover medication.

I also asked about various types of self-treatment specifically for seizures. Table 4.10 shows that stress reduction techniques and diet had been tried by about one quarter of respondents, and another tenth had tried vitamins to affect their seizures. Taken together, 42% of those interviewed said they had tried one or more of these self-treatment activities on their own for seizures. These were least likely to have been used by the young and the old: less than a third of those under 29 said they had tried, and less than a fifth of those over 50, while people between 30 and 49 were divided equally among those who had and had not. Self-treatment did not vary by people's sex, income, or education, and did not affect changing or stopping medications, or having leftover prescriptions. Self care was less common among incident cases (34%) than among non-incident cases (51%), but this difference was not statistically significant (Corrected $X^2=2.9$, df=1, $p<.09$). Nonetheless, it does suggest that Rochester residents who are diagnosed as having epilepsy are less likely to use non-biomedical treatments than are those who move into Rochester after being diagnosed. This is probably an effect of the Mayo Clinic's presence in town, and suggests again that estimates of self-care for epilepsy would be higher based on studies in other areas.

Another category of self-care discussed in the last chapter is that of recourse to other alternative sources of care. I asked people whether they had sought help for their seizures from pharmacists (other than filling a prescription), priests or other religious leaders, epilepsy self-help groups, chiropractors, nutritionists, health food stores, biofeedback therapists, or acupuncturists. (No-one said they had had acupuncture for their seizures, but while the study was in progress a chiropractor in the state did advertise acupuncture as a cure for seizures.) The proportions of respondents who used these resources are also shown in Table 4.10. Recourse to these sources of care was not associated with age, education, sex, income, or residence at diagnosis, nor was it associated with stopping medications or changing dosages. This may be because the categories of help are so varied: chiropractors give direct therapy, while pharmacists (in this question) give information, and priests give emotional and spiritual support. The individual totals are too small to examine separately, but it is also probably unreasonable to expect that lumping these different kinds of resources together can reveal consistent associations with demographic or regimen-related variables.

Table 4.10
Other Resources for Care or Advice about Seizures

Specialists:	Percent of 127
Pharmacist (other than filling a prescription)	17%
Priest etc.	12
Epilepsy group	10
Chiropractor	10
(Other: nutritionist, health food, biofeedback)	5
Any of the above	37%

Self-treatment	Percent of 127
Stress reduction	28%
Diet	23
Vitamins	11
Any of the above	42%

Summary

Self-regulating medical regimens is a common phenomenon, since almost 60% of interviewees said they had either stopped medications for more than three days at a time and then went back on, discontinued them completely, or changed the dosage for more than two weeks. Twenty percent of interviewees had followed an altered regimen in the week before the interview; if those who had already discontinued on their own were included, this proportion would rise to 33%.

People who changed the dose for more than two weeks most frequently said they did so because they felt discomfort from medication side effects, or felt they were doing well and needed less medication than had been prescribed. In contrast, people who stopped their medications mentioned side effects only rarely, concentrating most often on whether they still had the condition. This is a basic difference between the strategies: changing the dose involves evaluating the regimen; stopping the dose involves evaluating the illness itself.

Testing to see whether one still has epilepsy is a common reaction to the condition. Patients are more prone to test than physicians are, and they use their medications to diagnose themselves much as the neurologist uses the EEG. Some patients also appear to have definitions of health which differ from their physicians': physicians define health as the absence of seizures, while some patients define health as the _relative_ absence of seizures. Some patients take a personal approach to their physicians, adjusting their own level of responsibility according to their perceptions of their physician's ongoing interest in their case. Others take a more objective stance, assessing their regimen according to concepts of risk.

Faith in medications is an important part of an ongoing regimen. Little faith in medication can cause people to increase the dose or to discontinue it entirely. However, some people are so committed to the regimen that a physician's suggestion they might consider stopping it is enough to send them to another doctor.

About 40% of respondents had used various kinds of self-treatment not specifically recommended by physicians, and about the same proportion had been to a variety of non-physician specialists for care. These resources were used at the same time that medications were being taken and physicians being consulted, so they usually supplemented rather than replaced biomedical therapy for epilepsy.

Both this chapter and the preceding one have dealt primarily with the _therapeutic_ side of managing epilepsy--what people do in order to diagnose and treat their seizures. The next two chapters discuss the _ministrative_ side of managing epilepsy--what people do to integrate into everyday social life their physiological problem, its care, and the problems arising from both of these.

CHAPTER FIVE: STIGMA AND SOCIAL SANCTIONS

Introduction

> #157
> I use the word blackout--if you say 'convulsive disorder' people get upset. ...when a person hears the word 'epilepsy' you really think it's really really bad. Saying 'blackout' makes it not seem quite so bad.

> #246
> My doctors used the term 'convulsive disorder' for a long time. I started calling it epilepsy before they did. They didn't seem to like that term. I finally had to ask them if it was epilepsy.

What sort of a disease is epilepsy that it should prompt such careful labelling? Although Susan Sontag has written that chronic diseases like cancer and tuberculosis have become "encumbered by the trappings of metaphor" (1978), epilepsy is more often encumbered by euphemism than metaphor. We use the word "fit" as a metaphor for strong emotion ("a fit of anger") much as we use the word "schizophrenic" to signify unpredictable action ("a schizophrenic stock market"). Yet epilepsy is not commonly used as a metaphor for uncertainty, unpredictability, or other images that one might expect would associate with it. Perhaps other terms more closely connected with mental illness provide more powerful substitutes, or perhaps public uncertainty over what epilepsy is limits the metaphoric power of the word.

One interviewee (#252) questioned the value of euphemisms for epilepsy: "So many call it 'seizure disorder'. It would be like someone with cancer going around saying 'I have a malignancy, I don't have cancer.' Why be touchy about a synonym?" This chapter explores why many people with epilepsy are "touchy" about their diagnosis: it describes the types of stigma and social sanctions people with epilepsy appear to face in all societies. People with epilepsy in almost all cultures are generally described as having low social status: high levels of under- and unemployment, high levels of suicide, low incomes, or high life dissatisfaction (see, e.g., Volume II of the 1978 Report of the U.S. Commission for the Control of Epilepsy and its Consequences). To have epilepsy is to join this unfortunate group, and thereby open oneself to the full force of past and contemporary social misunderstanding. Much as people with leprosy began to use the term "Hansen's Disease" in an effort to escape the stigma of leprosy (Gussow and Tracy 1968), people who describe themselves as having a seizure disorder rather than epilepsy try to dissociate themselves from negative attributes.

Euphemism surrounds epilepsy even in the clinic. Doctors often avoid diagnosing "epilepsy," instead substituting labels like "convulsive disorder," "seizure disorder," and "lapses of consciousness." Physicians in Greece write: "we now avoid the word 'epilepsy', at least in the first sessions, because of the macabre folklore still attached to this illness in Greece: we use vague terms such as 'excessive activity of the brain' with simple metaphors from everyday life" (Gregoriades 1972:16). Even when they do diagnose epilepsy, physicians may urge their patients to deny the label. A U.S. physician reported that "at several epilepsy self-help meetings in the past few months, fully 80% of people attending have been warned by their neurologist to deny or cover up the diagnoses of epilepsy in order to deal with employers or insurance companies" (Riley 1980:644). As Chapter One reported, denial of diagnosis affects even community surveys to assess the prevalence of epilepsy: an Australian survey found that 23% of people whose epilepsy was described in clinic records denied they had the condition (Beran et al. 1985b:83).

Such denials are not always willful. Some portion of these people may not ever have been told they had epilepsy. Patients reproduce the careful words chosen by their physicians, and add their own terms like "blackouts," "sleeping spells," and "lapses of consciousness." A study in England found that 18% of those interviewed thought their seizures were not epileptic, though all had had multiple generalized seizures (Hopkins and Scambler 1977:184). As part of the Rochester interview we asked people to tell us what word they commonly used to describe their seizure. We sometimes got responses like (#242) "My doctor said 'you don't have epilepsy--you have a seizure disorder, which can be controlled by Dilantin.'" (This wrongly implies that epilepsy means "uncontrollable seizures.") Another reported receiving similarly tailored diagnoses, though she knew her condition was not a "normal" illness:

> # 154
> I just have a problem. I don't know why. They still haven't said 'you're an epileptic.' They say 'because you've had it this many years you must have a seizure disorder, but we don't know what it is.' But it's still abnormal--if you fall and break your leg, that's normal--this isn't.

Rochester residents described their seizures to interviewers using a large variety of terms, including epileptic seizure, seizure, seizure disorder, fainting or dizzy spell, zonking out, passing out, sleeping spells, blackouts, popping off, and jumps. Other studies have found a similar variety of terms employed by people with epilepsy, caused by the careful labelling of patients and physicians, misunderstanding, and willful misleading (Scambler and Hopkins 1986:35, Schneider and Conrad 1983:153-4, West 1986:256).

Chapter Four, on medication use, looked at discontinuing medications as part of a process of evaluating whether people still felt they "had" epilepsy. The following discussion of stigma and sanctions will give additional details about why people might be anxious to test whether they still have the condition.

I will begin by reviewing concepts like stigma, deviance, and sanctions, used by social scientists to discuss the origins and transmissions of negative judgments about particular groups of people. Then I will discuss the methods that have been used to describe the social functioning of people with epilepsy, together with the kinds of results they have obtained. This is important because there is controversy over whether epilepsy is indeed as stigmatized as many researchers have said. I conclude that epilepsy appears to be stigmatized across cultures, but different research methods bring different estimates of the extent and type of this stigma.

What is stigma?

Stigma were the signs used by the Greeks to mark slaves, criminals, or other disvalued persons. To stigmatize thus means to label negatively. The concept of stigma was introduced into social science by Goffman in his book *Stigma: Notes on the Management of Spoiled Identity* (1963); much work on the topic since then uses Goffman's seminal ideas to analyze particular health conditions (see e.g., Ablon 1981, Ainlay et al. 1986, Edgerton 1967, Schneider and Conrad 1980). Goffman defines stigma as a relationship between "an attribute that is deeply discrediting" (1963:4) and a social expectation or stereotype; an attribute is discrediting because it is "undesired differentness from what we had anticipated" (Ibid.:5). Attributes can be stigmatized in some situations but not stigmatized in others (a man with two missing fingers will be noticed at a tea party, but not when at work on an oil rig). Stigma depends on context because it varies according to people's expectations, their perceptions of socially devalued attributes, and the intrusiveness of the attributes.

Goffman points out that attributes can be _discredited_ or _discreditable_--discredited traits are known, and cause tension because they must be either maneuvered around or addressed directly (Ibid.:41-42). Discreditable traits are usually invisible, and cause tension because they must be _managed_: people must decide whether to reveal them or not. Epilepsy is clearly discredit_able_, since it is episodic and leaves no signs of its existence to the untrained eye. Neurologists might look for scars, bitten cheeks, or signs of anticonvulsant side effects like hirsutism or gum growth, but these signs usually would go unnoticed by the layperson. In some cultures people with epilepsy bear more obvious marks: burns from where they have fallen into a fire (see e.g., Aall-Jilek 1965, Hoskin et al. 1969). Only in this instance are people visually marked and discredited as "epileptics" even when they are not having a seizure. The rest of the time people with epilepsy must decide whether, how, and when to make their condition known.

The literature on stigma is one subset of the sociological interest in _deviance_--a key sociological concept that can be defined as behavior perceived to break social rules. Goffman defines the topic of stigma largely to avoid problems with the sociology of deviance literature, particularly its propensity for calling all rule-breakers deviants, and thereby losing sight of the particular situations in which rule-breaking is and is not accepted. Some writers criticized the deviance literature for concentrating on behaviors (prostitution, homosexuality, violent crime) defined as deviant by middle class values. They suggest the deviance literature ignores phenomena like white collar crime and the abuses of the powerful (e.g., Liazos 1972, Bynder and New 1976). Others criticized Goffman for analyzing the social definitions of stigma but excluding individual perceptions and definitions of potentially stigmatized traits (e.g., Schneider and Conrad 1980, 1983). Another criticism of the concept of stigma is that it can be applied to both the discredited attribute and the negative label for the attribute, as well as the practice that creates the negative label. I will apply the term stigma to the negative label, and use the term "stigmatize" when referring to practices that create the label. Later I will refer to organized and diffuse sanctions: these anthropological concepts can help clarify the stigmatizing process. Stigma commonly refers to diffuse sanctions, but I will argue that the concept of organized sanctions provides another focus for understanding the social problems faced by people who have epilepsy or other chronic diseases.

Goffman said that the idea of stigma helped researchers to pay more attention to when rule-breaking was and was not accepted. An alternative to Goffman focusses on how people become defined as "rule-breakers," that is, how social reactions can produce continuing deviant behavior. "Labelling theory" argues that social reactions to illness, particularly mental illness, are more important to social adaptation than are any underlying dysfunctions (see e.g., Scheff 1966). In extreme form labelling theorists question the very existence of mental illness, suggesting that any underlying pathology is of minimal importance when compared with the force of social sanctions, especially institutionalization (see Szasz 1974, _The Myth of Mental Illness_). There are obvious parallels to epilepsy, especially since the label "epileptic" can be applied after only a few seizures, electrophysiologic correlates of seizures cannot always be measured, and the repercussions of labelling often outweigh any inherent physiologic impairments. Yet while it has become a truism to state that the social context of epilepsy is as or more important than the physiological, efforts to measure or explain outcomes like social and psychological adjustment among people with epilepsy rely almost exclusively on physiologic and clinical variables like seizure type and frequency, etiology, age at onset, and the like. Hermann and Whitman have found, for example, that almost 80% of the nondemographic variables examined as risk factors for psychopathology have been of this type (1986:6). Labelling would seem to be another potentially important construct in explaining the social and emotional problems of people with epilepsy.

Using stigma analogies

Some authors have argued that the stigma of epilepsy is analogous to that manifested toward people of different skin color (e.g., Bagley 1972, 1986). This argument is problematic, for discrimination based on skin color is maintained through systematic and long-standing exclusions from economic and political premiums, and is determined by social evaluations of inherited traits. Comparing racial stigma with stigma toward epilepsy ignores a crucial distinction between inherited and acquired traits. People with epilepsy do not marry endogamously, nor are their children automatically classified as "epileptics." People with other chronic health problems like cancer or colostomies, or discredited traits like severe burns, amputations, or spinal paralysis have physical traits held in low esteem, but their membership in stigmatized groups also is not transmitted by birth. These social defects are obtrusive but individual--acquired characteristics are not inherited, and are unlikely to be surrounded by supportive social networks. The causes of exclusions based on skin color must be sought in social and historical events, not in stigma, individual traits, or fears of difference.

Stigma and protest

When a group of people with physical disabilities organizes for political purposes, it elevates a particular disvalued trait for political ends. This requires minimizing other distinctions which might exist in the group. It may be why the disabled rights movement has come so late on the political scene: potential members must be convinced that the political benefits of joining the movement outweigh the considerable social risks of not only being but of purposefully labelling oneself disabled. Zola argues that the stigma of chronic disability can be more diffuse and difficult to manage than that directed toward minority groups; the chronically disabled are socially "invisible;" their fundamental claims to humanity can be questioned (Zola 1981a:358).

People with hidden chronic illnesses like epilepsy, hemophilia, or diabetes (discreditable illnesses) are even more difficult to organize: in order to be effective lobbyists or advocates these people must choose to identify with the illness label even though they can usually pass as normal. It is difficult to turn a disability into a positive attribute (see Anspach 1979). Zola asks "What about the chronically ill and disabled? Can we yell, 'Long live Cancer!' Up with Multiple Sclerosis! I'm glad I had Polio!" (1981a:358). Zola's point is important, but the prospect of political gain can serve to mobilize people regardless of whether the group possesses a store of positive images. While image enhancement may help, it is not a prerequisite for protest against social injustice or illegitimate legislative sanctions.

Chronic illness can be a means to informal as well as formal social protest. Disability can be strategically maneuvered: used to ward off pity, or to solicit it; to cause fear, or to assuage it; to obtain information, or to reveal it (Edgerton 1967, Scheper-Hughes and Lock 1986, Taussig 1980). Physiological impairments do not continuously disable, sometimes they empower, and/or lead to greater sensitivity or compassion. Stigma can be manipulated, and people's fears of a disability can be used against them: I interviewed a woman with epilepsy in New York who said she had threatened to have seizures when she wanted to get rapid service in stores and banks. Thus disability is socially constructed, situational, and subject to manipulation. In fact we use the term "malingerers" for those who have failed to acquire a legitimate label as disabled, but who continue to seek or employ it.

Just as we distinguish between inescapable and optional social labels, so too we can categorize illnesses into visible and invisible, discredited and discreditable to distinguish between unavoidable and avoidable confrontations with stigma. Avoiding stigma is a central issue for people with epilepsy, and will be dealt with at length in the following discussion. But we must separate the social effects of seizures from the social effects of illness chronicity, which has independent effects (Britten et al. 1986:237). Avoiding stigma is not unique to epilepsy: the concerns voiced by people with epilepsy will be relevant to other diseases with various degrees of similarity, e.g., chronic vs. chronic episodic illness, and stigmatized vs. unstigmatized illness (for examples categorized by these dimensions, see Table 5.1). People with other stigmatized episodic conditions face similar issues about whether to reveal their condition, what to do when it manifests itself, and how much their other social roles become affected by it. Chronic stigmatized disorders are somewhat different, since revealing them is not optional under most circumstances. People with unstigmatized chronic conditions may face many problems with medications or employment restrictions like those faced by people with epilepsy, but they may not have to endure similar interpersonal rejections.

Table 5.1
Disorders categorized by stigma and chronicity

	Stigmatized	Unstigmatized
Chronic	Cerebral Palsy Leprosy Mental Retardation	Diabetes Emphysema Hypertension
Episodic	Epilepsy Herpes Schizophrenia	Asthma Gout Hayfever

Some concerns of people with epilepsy can be generalized even more widely to other "dependency groups," an umbrella term suggested by Illsley to encompass the elderly, chronically ill, and handicapped (1981:328). Illsley groups these conditions together to highlight their similar features: they resist curative treatment and are costly to manage; are medically uninteresting; have multiple needs that require assistance from multiple professions; and cause people to become economically and socially dependent. Bureaucratic sanctions applied to epilepsy are probably more relevant to these groups than is the particular stigma toward epilepsy.

Stigma and sanctions

Stigma is manifested in many forms, from snubs by former friends to legislation governing fitness for employment. But while stigma is a common motivating force for bureaucratic rules and restrictive legislation, it is not the same as a sanction. Sanctions are commonly defined within anthropology as positive or negative reactions to modes of behavior--those I discuss are almost entirely actions of disapproval. These rewards and punishments are distinguished by Radcliffe-Brown (1952:205) into diffuse and organized types: "the former are spontaneous expressions of approval or disapproval by members of the community acting as individuals, while the latter are social actions carried out according to some traditional and recognized procedure." What I will call bureaucratic sanctions are those organized sanctions that may or may not be legitimized by law, like employment restrictions. These can be distinguished from legislative sanctions like driving restrictions. Though they may change through time, legislative sanctions have the force of law buttressing their legitimacy. Managing diffuse sanctions requires adopting particular strategies of impression management and disclosure--threatening situations can arise daily. Organized sanctions get confronted less often, and under specific circumstances: applying for an insurance policy, a driver's license.

Studies of stigma among people with epilepsy provide conflicting results, and often catalogue either proportions of people who feel they have been discriminated against, or the strategies they use to manage discreditable information. Both of these are important efforts: the first helps outline the extent of the problem of stigma, and the second illuminates how people feel about it and manage it in everyday life. But these studies must be supplemented by attempts to ascertain how and why stigma toward people with epilepsy is produced. To answer these criticisms the study of stigma and epilepsy must begin to focus on diffuse and organized sanctions, looking at the rationales and responses to each type. Describing how people with epilepsy manage stigma helps those of us without it to understand them, and may facilitate rehabilitation. But a sizeable portion of the stigma faced by people with epilepsy in the United States comes in the form of bureaucratic and legislative sanctions: stigma here has been rationalized, objectified, and codified into policies that exclude people with epilepsy from particular kinds of work or insurance, or from driving. While diffuse sanctions are by definition difficult to criticize with rational or empirical evidence, the procedures of organized sanctions can be critiqued, and the grounds for legislative sanctions in particular can be questioned and argued empirically.

Controlling illness or people? Physicians and sanctions

Part of the reason for physicians' careful use of the diagnosis "epilepsy" is that they have become the ultimate legitimators of many organized sanctions. Physicians not only diagnose and treat, but also decide fitness for work, school, driving, and other activities. The public, and most physicians, have come to view this as right and proper, since physicians are seen as impartial and scientific. But the "legitimating" task brings with it even more responsibility for proper diagnosis and evaluation, and changes the roles of physicians and patients. Physicians become evaluators and enforcers, while patients become supplicants petitioning for social premiums like driving licenses.

Some physicians object to their role as social evaluators. They suggest it diminishes the trust required for successful communication about intimate health-related details. For example, diagnosing "epilepsy" in six U.S. states legally requires a physician to report the condition to the motor vehicle department and thereby initiate a series of negative legislative sanctions. Physicians in most states have resisted this legislation, saying that a police role interferes with traditional medical standards of confidentiality, and causes patients to avoid medical treatment. Some physicians mix their roles as therapists and evaluators, for example when they hold out driving privileges as a reward for taking medications as directed. Once established, these sanctions are difficult to change--physicians see them as valuable tools in their practice; legislators see them as necessary to protect the public welfare; and patients see them as inevitable.

Some of these points are emphasized by Thomas Szasz, who concentrates his critique on external social constraints on the behavior of the ill. Szasz proposes that as medicine developed into a profession in this nation, a concern for controlling illness became transformed into a concern for controlling the _person_ who has the illness:

> In the initial decades of this century much was learned about epilepsy. As a result, physicians gained better control of the epileptic process... The desire to control the disease, however, seems to go hand-in-hand with the desire to control the diseased person. Thus, epileptics were both helped and harmed: they were benefited in so far as their illness was more accurately diagnosed and better treated; they were injured in so far as they, as persons, were stigmatized and socially segregated.
>
> Was the placement of epileptics in 'colonies' in their best interests? Or their exclusion from jobs, from driving automobiles, and from entering the United States as immigrants? It has taken decades of work, much of it still unfinished, to undo some of the oppressive social effects of 'medical progress' in epilepsy, and to restore the epileptic to the social status he enjoyed before his disease became so well understood. (_Whither Psychiatry?_ 1966)

If Szasz were correct in his major argument we should find high levels of social acceptance toward people with epilepsy in places that have little access to medical progress in epilepsy. The next section will show that this kind of social acceptance is rarely seen even in developing nations. Szasz makes an important point but overstates his case, since people with epilepsy were not well treated even in the past (see Lennox and Lennox 1960, Pasternak 1981, and Temkin 1971). In fact some authors even imply that the early medical treatment of epilepsy itself helped lead to greater social sanctions: the bromides used in the mid-18th century caused mental sluggishness, which helped epilepsy to become associated with dullness and low intelligence, and made it a target for eugenic restrictions (Barrow and Fabing 1956:5).

Szasz emphasizes contemporary formal controls on the behavior of people with epilepsy, but these have also been accompanied by invisible controls like surrender and withdrawal. Michel Foucault's important work on the history of ideas about confinement and mental illness, Madness and Civilization, traces how social control of the mentally ill evolved from tolerance and free movement to intolerance and confinement, to the contemporary world where confinement has become internalized. Society has eliminated the need for large scale confinement of the mentally ill by substituting an ideology of self-restraint and self-recrimination. Confinement becomes internalized when individuals adopt this ideology of moral responsibility for their illness. Foucault writes that in the contemporary world, "For the first time, institutions of morality are established in which an astonishing synthesis of moral obligation and civil law is affected" (1973:60). Society rationalizes this restraint, and turns overt condemnation into pity: "Our philanthropy prefers to recognize the signs of a benevolence toward sickness where there is only a condemnation of idleness" (1973:46). Epilepsy has been described as a moral condition by Schneider and Conrad (1983:147-149), but what they call its "moral aspects" focus primarily on its negative attributes: its undesirability and history of stigma, and impact on self and others' reactions. Foucault uses morality in a more encompassing way to describe how society masks rejection, and defines its own discomfort with incapacity and difference in terms of individual responsibility and self-recrimination. The outcomes are clearly seen in the words of one female Rochester resident who had complex partial seizures:

> (#113)
> My doctor says these are seizures--something not controlled from me, but from body chemistry. But my social worker says these are anxiety attacks. I think that means I cause them myself--they're my fault. Right now I think they are anxiety attacks, but my doctor...most people think that their doctor is God, so I guess since he said they're seizures, they're seizures. So...whatever he says, goes. But I just wonder if they are anxiety attacks. Like wondering why I'd think I'd not had one in a while, then have one later, just a few hours after thinking about it.

Social prejudices against people with epilepsy were ameliorated by modern clinical science, but in turn the epileptic is now seen to be sick rather than possessed, and therefore still barred from some social activities and interactions. In a society dominated by the need to be economically productive, sicknesses like epilepsy can interfere with social life just as completely as possession by demons once did (Aird and Woodbury 1974, Pasternak 1981).

IS EPILEPSY STIGMATIZED?
CROSS-CULTURAL EVIDENCE OF STIGMA AND SOCIAL SANCTIONS

There are many cross-cultural similarities in images describing epilepsy and in attitudes towards it. Most cultures, including our own, fail to recognize non-generalized seizures as forms of epilepsy. People whose seizures are labelled epileptic commonly face social discrimination, having reduced employment opportunities and being socially isolated. Generalized seizures are often feared and misunderstood. Popular theories of causation vary somewhat, with industrialized cultures relying more commonly on physiological or emotional causes (birth trauma, accidents, emotional stress), and non-industrialized cultures referring to contagious or spiritual causes. These etiologic categories produce some different social responses toward people with epilepsy, though these responses still convey stigma. Belief in a physiologic or psychologic cause prompts labels of physical or mental incompetence, while belief in a contagious cause prompts social quarantine.

These general conclusions about kinds and levels of social stigma across cultures come from five different kinds of investigations: public opinion surveys among the general population; opinion surveys among people with epilepsy; longitudinal studies of people with epilepsy using external measures rather than self-reported problems; qualitative research based on observation or key informant interviewing, and finally, descriptions of restrictive legislation targeted specifically at people with epilepsy. Each of these methods has particular problems and advantages that influence the utility of the information they produce, but their particularities have commonly been ignored in discussions of epilepsy and stigma.

Public opinion surveys among people without epilepsy

Public opinion polls are a common way to assess social attitudes. However, people asked provocative questions in public opinion surveys frequently give what they think are socially "correct" or conventional answers. In addition, even when attitudes are correctly portrayed, much research has shown that professed attitudes and beliefs often have little correspondence to actual behavior (see the review by Bernard et al. 1984). Opinion polls are nonetheless one of the best ways to obtain a quick and rough estimate of public attitudes. Even if one assumes that opinions correspond only slightly to behavior, socially accepted behavior and accepted responses to questions about behavior do change. Surveys of public opinion provide useful data for education programs; if well-designed they can help define the boundaries of conventional ignorance and knowledge about causation, prognosis, and employability; and anchor later assessments of changes in these boundaries.

Public opinion surveys about epilepsy show that while attitudes toward people with the illness are becoming more enlightened, significant levels of prejudice remain in many countries. Surveys of opinions about epilepsy in the USA have been done every five years since 1949; these show decreased levels of prejudice over time toward people with epilepsy (Caveness and Gallup 1980). For example, from 1949 to 1979 the proportion of respondents who did not think epilepsy was a form of insanity went from 59% to 92%, and the proportion who thought people with epilepsy should be employed went from 45% to 79%. Questions about more personal issues still revealed significant levels of discrimination toward people with epilepsy: 18% of respondents in the 1979 survey said they would object to having their child marry a person who has seizures, while 68% said they would not object. More limited types of surveys state they have found high levels of misunderstanding about epilepsy (e.g., Hansotia et al. 1980 among clinic employees in Wisconsin, and studies reviewed in Dell 1986).

In England, Patrick West found that 114 respondents from a street survey claimed "sufferers [of epilepsy] were violent, unsociable, backward, highly-strung types to name but a few" (West 1979:728). About half of the respondents had had entirely negative experiences of people with epilepsy; 25% of these respondents thought that a person with epilepsy could become crazy or go berserk, and almost ten percent said they knew a person who died because of a seizure (Harrison and West 1977:282). Similar reports come from other industrialized countries. More than half of those in an Australian survey believed people with epilepsy should have limited participation in sports, one third thought they should not go on outings unescorted, and about 40% advocated some form of separate schooling (Vinson 1975:665). In Finland, about 20% said they would object to having their child play with a child with epilepsy (Iivanainen et al. 1980).

While levels of stigma are high in industrialized countries, some reviewers of the literature (e.g., Iivanainen et al. 1980) have said they are higher in developing countries. Many public opinion surveys in Africa suggest this is true. Interviews with 200 literate adults in Nigeria revealed what the authors labelled "a widespread negative attitude" toward people with epilepsy. Both sexes would rather not employ epileptics, and 35% felt the condition was caused by witchcraft (Awaritefe et al. 1985:6-8). In Sudan, 28% of 92 primary school teachers surveyed said they would not like to have a child with epilepsy in their school, and only 36% said they would treat such a child normally (Younis 1983:215). Similar reports of social stigma, and accompanying beliefs that epilepsy is contagious, come from the Baganda of southern Uganda (Orley 1970), the Wapogoro in what is now Tanzania (Aall-Jilek 1965), the Dogon people in Mali (Miletto 1981), the Bariba of Benin (Sargent 1982), and various groups in Madagascar (Terranova and Ratsifandrihamanana 1970) and Senegal (Adotevi and Stephany 1981). It appears that epilepsy is a stigmatized illness in most, if not all, of Africa. There are some conflicting reports: Ndiaye et al. (1983:347) cite Collomb et al. (1968) as suggesting that the attitude toward people with epilepsy in Senegal is "a mixture of interest, protectiveness, and wide tolerance". This, they say, is associated with the prevailing belief that epilepsy comes from spirit possession, and that someone possessed by spirits is chosen by them and therefore privileged. They also report, however, that some groups in Senegal do not hold customary reincarnation dances for deceased people who have had epilepsy, for their reincarnation is not desired (Ndiaye et al. 1983:348).

Opinion surveys among people who have epilepsy

Opinion surveys among people with epilepsy can help to give an 'inside' perspective on illness: how people who have the condition (the targets/ recipients of rehabilitation programs) feel about general public knowledge and attitudes, and how they evaluate education and rehabilitation programs. These surveys complement opinion surveys among the general public, but they also duplicate the same faults: much as there is a bias toward positive answers from the general public, there may be a bias toward negative answers from people with handicaps. Also, perceived stigma and discrimination can come from 'real' or 'perceived' events. Expecting discrimination may change individual behavior enough to cause the discrimination (self-fulfilling prophecy). For example, a seizure by a person who hides her illness may shock her coworkers, and cause them to mistrust her more than if her condition had been known all along. The diagnosis also may be blamed for problems which come from elsewhere (e.g., Rodin et al.'s [1977:38] comment "Since it is easier for the patient to blame seizures for his failure rather than to attribute it to intellectual limitations or personality problems, the misplaced stigma becomes perpetuated"). Finally, most surveys of opinion among people with epilepsy have used convenient sampling frames: hospital outpatient clinics, specialty epilepsy clinics, or social service agencies. These kinds of sources provide information about the subsample of people with epilepsy most likely to be having clinical or social problems, and therefore potentially exaggerate the level and kind of problems faced by people with epilepsy in the community.

Quite aside from how many people estimate they discriminate against people with epilepsy, most surveys of people with epilepsy show that significant numbers of people with the illness feel stigmatized. Some epilepsy researchers have distinguished between "enacted stigma," defined as instances of discrimination, and "felt stigma" defined as fear of enacted stigma combined with more general shame about having epilepsy (Scambler and Hopkins 1986). While it makes conceptual sense, Scambler and Hopkins nonetheless assess enacted stigma just as they assess felt stigma--by interviewee self-report. Their categories might better be labelled "perceived stigma" and "reported instances of stigma," to highlight how important respondents' perceptions are to this method. Scambler and Hopkins (1986) found their British respondents had significant levels of fear and shame about having epilepsy. For example, about a third of those who got married after their seizures began did not tell their prospective spouses about the condition, and another third mentioned it only using terms like "attacks," "dizzy spells," and so forth (1986:35). More than half had never told their employers about their epilepsy, though only 18% of those who had disclosed reported job-related incidents that impaired their career (1986:36-7). Scambler and Hopkins thus propose that "enacted stigma" has been overestimated: "felt stigma," they say, is a more important and devastating cause of problems. But even if actual stigmatizing incidents are overestimated (and I do not think they are), this is a "victim-blaming" explanation, for it implies that people with epilepsy themselves are responsible for their lower life achievement. Fear of exposure is debilitating, but it is shortsighted to conclude that fear of exposure is reasonable only if it develops <u>after</u> particular incidents of discrimination following disclosure. Where earning one's livelihood is concerned, avoiding incidents seems natural. In fact Scambler and Hopkins report that almost one fifth of those who disclosed could name job-related incidents: they imply this proportion is low, but it could just as easily support a contention that job-related stigma exists among employers and justifies fears of disclosure among employees with epilepsy.

If reports of actual incidents of discrimination are to be the measure of stigma, information from Australia provides clearer evidence. The Australian public surveys mentioned earlier documented high levels of discrimination, and reports from people with epilepsy bear this out. Fifty-eight percent of 160 outpatients with epilepsy complained that their social life was restricted, 39% felt their schooling was limited, and 44% felt their career was less successful than it would have been had they not had the disease (Edwards 1974:239-40). A later survey from Australia found about 40% of 51 patients from a neurology clinic reporting they had personally experienced job discrimination (Beran and Read 1981:63).

A survey in Oregon of 445 adults with epilepsy also concluded that stigma was perhaps not as important as previously thought, though it reported levels of enacted stigma far higher than Scambler and Hopkins: 81% of these respondents felt fairly treated by employers, 46% had at one time experienced employment discrimination, and 18% had experienced employment discrimination sufficient to engender a negative attitude toward employers (Ryan et al. 1980).

Similar reports come from two national surveys in the United States. Both of these surveys were based on formal epilepsy-related service networks however, so they are most representative of those people who were presently receiving social and/or medical care: those with more frequent seizures, greater needs, and/or greater willingness to seek assistance.

For example, 44% of the adults in one of the surveys (Perlman 1977) had seizures once a month or more, while only 16% of the respondents in Rochester said they had seizures this often. The first survey (Perlman 1977) sampled the National Epilepsy League's pharmacy service, with a 56% response rate or 363 questionnaires returned. One quarter of respondents to this survey did not tell their employers about epilepsy, half of those currently working said that having epilepsy had created problems in getting a job, and 40% of respondents reported they had found laws to be unfair to those with epilepsy (Perlman 1977). The second survey involved 3000 questionnaires distributed through epilepsy self-help groups and Epilepsy Foundation affiliates. Only 357 were returned, for a response rate of about 12%. Asked what was the single greatest problem they had experienced because of their epilepsy, 22% mentioned emotional problems, 21% job-related problems, 13% lifestyle restrictions, and 12% driving restrictions (Arntson et al. 1986, Droge 1983:142).

Reports from Africa about people with epilepsy differ somewhat by country and urban versus rural residence. In South Africa, members of the Nguni tribe who had epilepsy reported they were generally accepted by people around them. Less than 20% of 118 respondents claimed they were avoided by people outside the family, yet almost 30% of 155 respondents had left or not attended school because of epilepsy, and 45% of 130 felt overprotected or rejected by their families (Newton and Gero 1984:22). Ndiaye et al. (1983) suggest that labor surpluses in urban areas compared with rural areas will cause urban areas to have higher levels of employment discrimination toward people with epilepsy.

In Japan, Soga et al. (1980) report that 22% of their respondents with epilepsy concealed their disease from others, and 36% reported troubles in their family. Higashi et al., in a survey of 2000 patients from an epilepsy referral center found marriage rates below the Japanese norm: 22% of males and 33.1% of females over 18 were married (1979:404). Yamada et al. found low marriage rates for females (1980:306). Income and education levels appeared equivalent to average Japanese levels, though measures were imprecise and average levels were not presented.

Opinion surveys among people with epilepsy reveal a fairly consistent picture of reported emotional, occupational, and educational problems, along with a range of social concerns around stigma, marriage, friendship, and family relations. A few authors have questioned whether these reported problems arise more from the actions of the outside world, or the expectations of the person with epilepsy. The answer, of course, is that both are involved: people who have not experienced stigma can still be taught that their condition is shameful and not to be disclosed, and people can have negative experiences that convince them that further disclosures are unwarranted. What is most important about these various studies is not whether fear comes from within or without, nor whether they describe their samples accurately, but rather what conclusions are drawn from them about the general universe of people with epilepsy. Clinic samples describe epilepsy as experienced by people under medical care, but this is only one portion of the population with the disorder.

Longitudinal studies

Longitudinal studies of people with epilepsy that use external 'objective' measures of social status and discrimination avoid the uncertainties associated with self-reported stigma, but often sacrifice sensitivity in exchange for greater objectivity. Using school records to assess a child's 'visibility' in the classroom, or number of firings to measure impediments to career advancement, may avoid the subjective interpretations of opinion surveys, but these factors may not be important to life success. While longitudinal studies usually use samples more representative of unselected populations, they also face potential problems over time such as losses to follow-up. In some instances, for example comparisons among subgroups, losses to follow-up can make samples small and unrepresentative, and reduce the likelihood that important differences will be measured as statistically significant.

Because of their duration and complexity, and resulting expense, only a few longitudinal studies of epilepsy have been done. In England Harrison and Taylor reported following 179 of 628 children for 25 years after their first seizures. They found that two thirds of the group had had minimal or no ill-effects from their seizures, but the consequences for the remaining third were serious: "so serious as to explain why 'epilepsy' frightens so much" (1976:951). Ten percent of the group had died, 10% of the survivors were institutionalized, and just under seven percent were invalids at home. Those whose epilepsy had continued were over-represented in low skill, low-income occupations and under-represented in those of high skill and high income.

In contrast, another British study of educational and occupational attainment among 46 cases followed for 36 years concluded that epilepsy was "much less disruptive" of achievement in these areas than the authors had expected. The epilepsy group as a whole had lower educational qualifications than the normal controls, but this difference was not statistically significant for a subgroup with idiopathic epilepsy (Britten et al. 1984, 1986:238). There was no evidence for poorer occupational attainment measured in terms of social class at age 26 for cases compared to controls matched by sex, father's social class, and area of residence

(1986:238). Children with epilepsy were reported in their school records significantly more often as being more aggressive and seeking of attention than controls, but their behaviors were not rated as significantly different on seventeen other behavior ratings (Ibid.:234-5). Emotional disturbance measured by seeking treatment was significantly more common in the epilepsy group (18% of 39) than it was in the non-epilepsy group (6.8% of 4572) (Ibid.). When members of the cohort were aged 36, significantly more of those with idiopathic epilepsy compared with controls felt life had not been good to them and felt discontent with their work, but they did not feel different about their education and family (Ibid.:239).

Despite their potential, longitudinal surveys have not yet provided solid conclusions about the relative contributions of neurological impairments, social stigma, socioeconomic status, and like factors to later life achievements among people with epilepsy. Longitudinal surveys have shown epilepsy's toll in death and institutionalization, which may in itself partially explain the image of the disorder as a disabling and frightening mental infirmity. Part of the confusion over the effects of epilepsy may be heightened by its association with other, more disabling, neurologic problems.

Qualitative research

Qualitative research based on observation or open-ended interviews can provide some of the most valid and reliable reports of social discrimination, but what this research gains in reliability it frequently sacrifices in generalizability. Qualitative researchers commonly spend little time on sampling concerns, selecting instead from conveniently available clinics, networks of acquaintances, and the like. This is completely justifiable early in a research effort when one needs to know variation and range of behavior, later in a study when one needs to examine a particular sub-group more carefully, or anytime one's concern is to reveal motivations and emotions rather than assess their frequency. It is not adequate when one's goal is to generalize to other people in other places. The small numbers of cases that can be managed using qualitative techniques make it difficult to know whether observed differences represent general patterns, random variations, or selection factors.

Published observational studies of people with epilepsy outside the clinic are rare, limited to West's (1976, 1979) repeated visits with 24 families in England, those by Mulder and Suurmeijer (1977) with 12 families in Netherlands, Peters' (1978) study of 16 families in Germany, and Trostle et al.'s (1983) visits with 8 families in New York City. All the studies except that of Mulder and Suurmeijer involved repeated visits, and all documented the strong impact of epilepsy on the family, and the relatively limited role that physicians play in the ongoing social management of the condition. These studies are based in observation rather than report, and provide some of the strongest evidence that epilepsy has a dramatic impact on families.

Other investigators have also used qualitative methods for their studies, though their observations are more commonly based in single encounters with informants or residence in an area. Neutra et al. (1977) found that although the Navajo distinguished three distinct types of seizure syndromes, they had no demonstrable excess prevalence of epilepsy. Their diagnostic divisions thus did not seem driven by greater familiarity with the illness. Navajo with epilepsy had more social problems (especially as subjects of rape and other violence) than did Navajo who had non-organic seizures similar in form to some of the epileptic seizures. Organic seizure problems lasted longer than psychological ones, and exposed people to more severe types of social discrimination.

Reports from Senegal and Mali suggest that only generalized seizures are defined as epilepsy--neither focal nor other partial seizures are viewed as sickness (Adotevi and Stephany 1981:285, Miletto 1981:293). The person with epilepsy is thought to die with each seizure, and then be reborn afterward. Miletto reports that although his informants told him that epilepsy was hereditary, it was treated as though it were contagious, with family members refusing to eat with the affected person, and those around a person having a seizure running away unless the person needs to be pulled from a fire or body of water (1981:295). In the Gazelle Peninsula in New Guinea, people with epilepsy face a broad series of sanctions, including limits to the foods they may eat at feasts, their proximity to water or fire, and their participation in dances and gardening (Hoskin et al. 1969:44). Hoskin et al. report that this leads to a life of enforced invalidism, social isolation, and dependence on family (Ibid.:45). In Madagascar epilepsy is seen both as contagious and as caused by spirits (Terranova and Ratsifandrihamanana 1970: 214). Individuals with generalized seizures are expelled from their clan, and not allowed even to be buried in the family tomb (Ibid.). These investigators report that complex partial seizures are interpreted as cases of possession by ancestral spirits; they are not brought in for medical consultation. However, absence seizures were brought into the medical system (Ibid.:218).

Qualitative research provides some of the harshest examples of discrimination toward people with epilepsy, but it is among the most difficult types of research to evaluate. Examples of discrimination help establish variability in behavior across cultures, but they cannot establish typicality of behavior within a culture.

Legislative sanctions

Describing and comparing restrictive legislation may be the most accurate way to summarize and measure formal social sanctions, but it is also the broadest. Legislation is a process of transforming social conventions into codified restrictions of behavior, but as such it provides only a general picture of *potential* problems, not an accurate depiction of *real* problems. Legislation does not describe or predict real behavior much better than public opinion does, but it can be charted over time in the same way that changes in public opinion can be surveyed. It provides an accurate relative--but not absolute--representation of changes in attitudes and beliefs about epilepsy.

Industrialized cultures may disavow contagious transmission of epilepsy, but they replace social quarantine with other rationalized bureaucratic sanctions that may be equally damaging. Many of the legislative sanctions enacted in the first half of this century in the United States were based on the eugenics movement, which lumped epilepsy together with mental illness and criminal behavior. Discrimination occurred in areas of marriage, involuntary sterilization or institutionalization, adoption, immigration, driving privileges, insurance, and employment. In 1956, 17 U.S. states had statutes prohibiting people with epilepsy from marrying, and five states had legal sanctions should such marriages take place (Barrow and Fabing 1956:12). (The maximum penalty was in Washington, where transgressors faced a 1,000 dollar fine and/or three years in jail.) Eighteen states at this same time had laws permitting the sterilization of people with epilepsy, and in four of these states the statutes applied to institutionalized and non-institutionalized groups (Ibid.:29). Immigrants with epilepsy could be excluded from the U.S. under federal immigration statutes (Ibid.:88). Barrow and Fabing emphasize that none of the marriage or sterilization statutes defined epilepsy, and none considered whether a person's seizures were controlled (Ibid.:32-33).

These statutes have slowly been repealed. Until 1982 it was a crime in Missouri to solemnize a marriage if that person knew that one of the parties had epilepsy (Epilepsy Foundation of America 1985:24). Delaware and South Carolina still have laws allowing people with epilepsy to be involuntarily sterilized, and South Carolina allows involuntary sterilizations on those who are institutionalized (EFA 1985:35). According to the EFA, forty-eight states and the District of Columbia have laws prohibiting employment discrimination based on handicap. Arizona, Delaware, Puerto Rico, and the Virgin Islands still do not prohibit such discrimination. As recently as 1981 Swarthmore College in Pennsylvania dismissed a student because he was having occasional seizures (Eichenwald 1987).

Summary

In the ideal world research methods would be used for purposes that maximize their strengths. For example, population-based surveys of epilepsy would be used when population-based estimates of the variability in and prevalence of social problems were needed. Service-based surveys would be used to guide rehabilitation agencies and other service providers, but not to draw conclusions about the condition of all people with epilepsy. Legislation could be charted and public opinion surveyed to assess whether education programs have been successful. By relying on multiple data sources and survey types investigators could "triangulate" their studies of social problems (Denzin 1970, cited in West 1979).

The preceding evidence came from many different cultures and many different methods, but it is remarkably consistent: people recognized as having epilepsy (this usually means recognized as having generalized seizures) are generally subjected to social ostracism and given lower social status. How and why does this process happen? How, that is, do societies give organic symptoms meaning and differential value, and transform being different into being less worthy? This next section explores these questions.

HOW AND WHY IS EPILEPSY STIGMATIZED?

Does epilepsy convey an exalted status?

If in some cultures people with epilepsy play special valued roles, while in others they are devalued and considered ill, we could argue that cultures vary in how they tolerate epilepsy. But are there cultures in which people with epilepsy do play valued roles by virtue of their condition? The suggestion that they may is based on a literature of long history in anthropology, written mostly about schizophrenia, which argues that the altered states of consciousness experienced by people with schizophrenia makes them uniquely suited to enter trance states, and to manifest behaviors such as convulsions, tremors, and other epileptiform manifestations appropriate for close contact with the spirit world (Ackerknecht 1943, Eliade 1964, Locke and Kelly 1985, Noll 1983, Silverman 1967). The social response here is positive rather than negative: seizures are still marked by society, but are interpreted as signs of competence for a valued social role rather than a marginalized and stigmatized one. This process has been suggested for epilepsy most recently and directly by Winkelman (1986), who writes that people with temporal lobe epilepsy also may have an easier time entering trance states.

Winkelman cites a number of studies to support his contention, arguing specifically that temporal lobe epilepsy is associated with a number of personality changes (emotional deepening, preoccupation with religion and philosophy, hyposexuality), and, by extension, that these changes are likely to ease entrance into, and performance of, trance-related activities (1986:184-187). A problem with Winkelman's hypothesis is that his evidence on epilepsy is more controversial than he admits. He writes that "there seems to be a general agreement that there is a link between temporal lobe syndromes and personality changes..." (1986:185), but both the studies he cites and the idea of a link between temporal lobe seizures and specific personality traits or disorders have received substantial criticism (see, e.g., the studies reviewed in Hermann and Whitman 1984).

Winkelman ends the section discussing temporal lobe syndromes and trance states by admitting that although his hypothesis is plausible, he knows of only one study (Aall-Jilek 1965, which he cites as Jilek-Aall) that measured whether trance practitioners actually had any evidence of epilepsy. In fact the Aall-Jilek study described a physician's impressions of epilepsy based on 110 patients from the Wapogoro tribe in what is now Tanzania--only one of these patients was a healer (_mganga_), and his father was also an _mganga_. The rest of the cases were said to be isolated within their communities, treated with hostility and cruelty (1965:65). Aall-Jilek writes "Theirs is a life full of loneliness and pain until one day they succumb to general infirmity and perish by falling into the fire or water" (Ibid.). Thus there is no evidence in Winkelman's paper that people with epilepsy enjoy some exalted status by virtue of their epilepsy.

At least one study not cited by Winkelman (Neutra, Levy and Parker 1977), examined, among other issues, whether Navajo trance practitioners had epilepsy. These researchers concluded that although the Navajo have a special role for 'hand-trembling' as a diagnostic specialty, neither people with epilepsy nor those with trembling hands associated with hysteria commonly adopted the role, which appeared to be allocated according to family ties rather than symptoms. Thus even if there *is* a social curative role allocated to people who seize, it was not filled by people with epilepsy, and only rarely filled by people whose seizures were thought to have a psychological cause.

If not an exalted status, does epilepsy convey some other special, non-stigmatized status?

One report that does link epilepsy with special status is a semi-fictional biography (Watson 1982) of a colorful character named Adrian Boshier, who spent time in the South African veldt living off the land, catching snakes, and collecting paleolithic artifacts for the paleontologist Raymond Dart, the discoverer of Australopithecus. Boshier had epilepsy, and Watson reports that it was the combination of the snake handling and the epilepsy that gave Boshier special status among the natives:

> In Africa the epileptic myth is one that sees the symptoms as evidence of supernatural possession. Anyone who has such a seizure is regarded, not so much as afflicted, as blessed by the spirits. An epileptic is someone to be cherished and encouraged rather than made to feel unwelcome, difficult, dangerous, embarrassing, or even unemployable. ...the epileptic, far from being a social outcast, frequently becomes an individual with a special and respected place in society, most often as a spirit-diviner (1982:88).

Reports like these employ rhetorical excesses that invert the negative stigma of the research presented earlier in this chapter. Watson portrays epilepsy in an idealized and positive image that is far from true, but his excesses portray some of the rationale for the view that epilepsy conveys an exalted status rather than a stigmatized one.

Even if an exalted role is not available to people with epilepsy, the possibility still exists that the causal frameworks of some groups allow them to treat epilepsy in a less stigmatized fashion. This is described for Senegal and the Ivory Coast by Ndiaye et al. (1983), who say that cultural explanations for epilepsy among some groups in these areas single out not the person with epilepsy, but rather the entity (neighbor, witch doctor, or spirit) who caused the epilepsy. The reasons for epilepsy are sought in social conflicts, not individual failures of physiology or will:

> The sufferer is than considered as the bearer of a message and inspires neither fear nor aggression. He is listened to and recognized by the group and his condition is everyone's concern. In that case the traditional cure is directed to the troublemaker and not to the epileptic (1983:349).

This would appear to reduce our Western tendency (discussed earlier in the section on Szasz and Foucault) to blame the affected person, and hold him or her responsible for the illness.

One other potential status can be seen that holds epilepsy to be less stigmatizing while still not exalted: this is the notion that epilepsy is more common among highly intelligent and/or creative people, that it gives people clear visions of realms closed to the rest of us. This was an idea Dostoevsky had Prince Myshkin express in The Idiot:

> You all, healthy people, he said, can't imagine the happiness which we epileptics feel during the second before our fit. Mahomet, in his Koran, said he had seen Paradise and had gone into it. All these stupid clever men are quite sure that he was a liar and a charlatan. But no, he did not lie, he really had been in Paradise during an attack of epilepsy; he was a victim of this disease like I was. I don't know if this felicity lasts for seconds, hours or months, but, believe me, for all the joys that life may bring, I would not exchange this one.

While an alluring image to adopt, this label can be as debilitating as the others (Zola 1981a, 1982). Most people with epilepsy will find they are not geniuses, artists, visionaries, or prophets, and will endure the disability without the imagined compensations. One middle-aged woman who had had seizures since early adolescence described her private struggle with this image:

> #135 I was discriminated against in school--my teachers thought I was lazy. When I was growing up I thought only geniuses had epilepsy. I SO much wanted that to be true. 'What do I have in common with them?', I wondered.

In this case what gets internalized is not responsibility for being ill, but instead self-recrimination for not living up to the positive attributes that are supposed to accompany affliction. Having the disorder but not its presumed compensations is a double stigma.

Why is epilepsy stigmatized?

Before predicting what social roles will be available to a person with seizures in any particular culture, we need to know how seizures are perceived (which ones are noticed) and how they are interpreted (which ones are dangerous, which not; which ones come from brain, which from spirit, which from mind). Only after we understand these reactions to seizures can we investigate how they get transmuted into medical diagnoses, behavioral expectations, and social roles. Reactions to seizures may draw their content from basic values unrelated to seizures *per se*: they may be based on cultural rules that define what is proper behavior. Lack of control and unpredictability can be tolerated, despised, or valued; disability can be tolerated or shunned; illness can interfere with or be irrelevant to daily activities (consider the different impact of physical handicap in a hunting/gathering society and an industrialized society). Seizures may be labelled with more and less stigmatizing terms (e.g., dying, sleeping, having a spell, rapture). These potential reactions can all differ across cultures, and can help to focus attention on particular issues, labels, or analogies. Which ones, then, are brought to our attention, and why?

Two different mechanisms help to create and maintain stigma toward people with epilepsy: first is the recognition (or perception) that convulsions accompany other severe disabling conditions (retardation, cerebral palsy, other neurological impairments), and therefore are associated with institutionalization, early mortality, and/or social incapacity. This causes people to fear epilepsy's physical effects in addition to fearing individual seizures. In addition to inspiring such fear in others, these physiological accompaniments to epilepsy may also themselves interfere with learning, memory, attention, and the like. Convulsions are threatening in themselves, and threatening for what they imply about these other limitations.

Generalized convulsions are socially significant despite whether they are associated with other impairments. Their recurrence commonly cannot be predicted, they flagrantly break rules about proper behavior, they are so uncontrolled and apparently self-destructive as to demand a response. In short, having had a convulsion means one continues to have an unpredictable ability to disrupt normal social intercourse. Again this has individual and general social outcomes: others may react negatively to knowledge of this ability, and withhold desirable social premiums like friendship or employment. But the person with epilepsy may also react negatively, and create a series of covering stories or avoidance strategies to keep the diagnosis secret. Goffman has pointed out that when rules of conduct are broken, both actor and recipient are threatened (1959)--knowledge that one person may at any time break these rules is similarly threatening to both parties, especially where cultural rules prize predictability and conformity.

Different kinds of physical and mental impairments meet varying levels of social disapproval within cultures, and there is no reason to suppose these responses do not also vary between cultures. We know different cultures prize different areas of the body, so the same disfigurement would meet with different responses. Why then does epilepsy appear to meet such universal levels of discrimination? In part this discrimination appears universal because I have concentrated upon whole-body convulsions, the most blatant, and therefore most commonly recognized, kind of seizure. If reactions to non-convulsive seizures were also compiled, considerably more variability would emerge, but this would force us to deal with a large and confusing array of diagnoses, causes, and symptoms. For example, a large literature exists on "nervios," among Hispanics, "falling out," among Southern US blacks, and "<u>indisposition</u>," among Haitians--these are labels for sudden losses of muscle tone, motor control, or sudden dizziness or loss of vision that are culturally-appropriate reactions to stress (Garrison 1977, Low 1985, Sal y Rosas 1966, Stevenson 1977, Weidman 1979). At least one of these studies stated that some of the cases might also have been diagnosed as epilepsy (Weidman 1979:97). However, these labels rally social support networks more commonly than they do medical networks. "Nervios" may be a label applied in Latin America with as much precision as middle class white North Americans speak of "nervous breakdowns."

Another large body of literature describes physician's attempts to separate "organic" from "psychogenic" seizures (e.g., Finlayson and Lucas 1979, Glaser 1978, Gross 1979, Gumnit and Gates 1986, Williams et al. 1978). But these issues take us too far from the question of how epilepsy is stigmatized--generalized seizures are the primary sign of epilepsy recognized cross-culturally, and this discussion therefore must focus on generalized seizures. Here the crucial components of stigma appear to be unpredictability and dramatic loss of control.

Who gets defined as social outcasts, and how they are treated, reveals many themes in any culture: middle class North American whites are intolerant and fearful of weakness, incapacity, and imperfection, and value physical performance, beauty, and youth (Anderson and Bauwens 1981, Haber and Smith 1971, Stein 1979). Epileptic seizures suddenly transgress these values, revealing incapacity where we assumed "normal" capabilities lay. Convulsions threaten social conduct, and their unpredictability and sudden onset increase their disruptiveness.

The next chapter describes these themes more fully by linking them to the concerns expressed by people with epilepsy in Rochester.

CHAPTER SIX: THE CONCERNS OF ROCHESTER RESIDENTS

To bring Chapter Five's general discussion of stigma to a more specific level, this chapter explores the concerns voiced by Rochester residents, and compares them with a nationwide U.S. survey. Looking within a middle class white community like Rochester, epilepsy appears less problematic than generally described, but it still prompts a high level of concern. People in Rochester are less worried about stigma than people sampled from clinics or referral agencies, but are equally concerned about ongoing legislative sanctions they face. Having problems is associated with particular demographic, social, and clinical factors, for example, the negative effects of epilepsy appear to decrease as time since seizures and/or medications increases. The chapter closes by discussing the kinds of evidence that have been used to justify present and past sanctions. Ambiguity and moral judgments are visible even in the highly rationalized legislative sanctions employed against epilepsy in the USA. These are exemplified in the debate over driving privileges for people with epilepsy.

Epilepsy is subject to considerable levels of social stigma, manifested interpersonally and bureaucratically. Managing epilepsy means attending to the interpersonal concerns surrounding one's potential identity as an "epileptic": saving face, hiding identity, "preventive telling" (Schneider and Conrad 1980). It also means managing the bureaucratic and legislative sanctions surrounding one's diagnosis: whether and when a driver's license can be obtained; how much health, life, or car insurance will cost if it can be purchased at all; whether particular careers are possible (e.g., trucking or military service).

I have suggested that part of the disagreement over epilepsy's handicapping potential comes from the disparate research methods that have been used. Public opinion surveys are less likely to show significant levels of stigma than are surveys among people with a disorder. Among people with epilepsy, clinic- and service-based samples should show more severe problems than community-based samples because they draw on people who have current management problems, are more sorely afflicted, and/or less able to cope. So that I could compare the Rochester sample with other service-based samples, I used in my interview some questions from earlier provider-based studies. One study in particular, described in a dissertation by David Droge (1983), attempted to survey a national sample to discuss epilepsy self-help groups and social stigma. This is the best attempt yet to get a national sample of diagnosed respondents about these issues, so I will describe it more fully below, and compare it to the Rochester sample. I will call this the epilepsy network sample, to contrast it with the Rochester community sample.

Droge's project used a formal network of epilepsy service and support groups to distribute 3000 copies of a questionnaire: it was announced in newsletters of the Epilepsy Foundation of America and of the Epilepsy Self-Help Group Workshop, and was given to self-help group leaders, physicians, and social service professionals for their distribution. While 3000 questionnaires were to be distributed throughout the U.S., the 357 (12%) returned questionnaires came from only about half of the U.S. states, with more than half coming from six states. Three of these last six states had active and ongoing self-help programs. This survey cannot be called representative of the nation, but given its methods of distribution it can at least be said to represent a varied help-seeking population. A more recent description of this project reported that 67% of respondents had attended epilepsy self-help groups (Arntson et al. 1986:150), while this was reported by only 10% of respondents in Rochester.

Comparing community and epilepsy network samples

The Rochester and epilepsy network samples voiced similar concerns, but ranked them differently. Table 6.1 shows that only about 20% of respondents in Rochester and in the epilepsy network sample said their seizures had fairly or very strong effects on their current lives. One might expect that the effects of epilepsy would be greater for people presently taking anticonvulsant medications, since taking medication implies a continuing need for protection from seizures. However, estimates of seizure effects were quite similar despite the fact that 3% of Droge's respondents but 22% of Rochester respondents reported they were not taking anticonvulsant medications at the time of the survey. This may mean that people with seizures are reluctant to say seizures are important, or may mean that seizures for most people really are not that important when compared to other life events and concerns. A related interpretation is that seizures, as relatively rare and sporadic events, are less important than the ongoing problems of managing the diagnosis of epilepsy. This last interpretation is reinforced by the fact that while only 20% of Rochester residents reported fairly or very strong current effects from their seizures, 74% of Rochester residents reported current problems from their epilepsy, and 80% reported life differences they attributed to their epilepsy. Cross-tabulating these answers, all of those who reported fairly or very strong effects from seizures also reported having problems or life differences from epilepsy, while 67% of those with none or mild effects reported problems, and 75% of them reported life differences. Estimating that seizures are having a strong effect thus predicts estimates of current problems and life differences, but estimates that seizures are having a mild effect does not.

TABLE 6.1
Perceived current effects of seizures on respondent's lives

Rochester sample

Category	(% of 127)
Not at all	39%
Mildly	40
Fairly strongly	10
Very strongly	10
Don't know	1

Epilepsy network sample

Ranked severity		(% of 338)
1 or 2	(low)	50
3 or 4		28
5 or 6		11
7	(high)	11

Asked what was the greatest single current problem people faced because of their diagnosis, Rochester respondents most frequently said they had none, or mentioned emotional problems or driving (see Table 6.2). In the epilepsy network sample "none" was ranked last, while the top three problems were emotional, job-related, and miscellaneous other. This supports the idea that a community-based sample includes a wider range of illness severity and adjustment to social problems: the proportion of respondents mentioning emotional and job-related problems was twice as high in the epilepsy network sample as in the Rochester sample (43% vs. 21%); while the proportion of network respondents saying they had no problems was about one tenth of that proportion among Rochester residents (3% vs. 26%).

Table 6.2: Current greatest problem because of seizures

	Rochester		Network: Droge 1983	
Response	**(% of 127)**	**Rank**	**Rank**	**(% of 357)**
None	26	1	7	3
Driving	19	2	5	12
Emotional (Depression, fear)	12	3	1	22
Job-related	9	4	2	21
Medications (side effects, problems consuming)	8	5		--
Social acceptance	7	6		--
Other (each less than 3%)	19	7	3	18
Lifestyle restrictions	--		4	13
Marriage and family	--		6	3
Missing or don't know	0			8

When asked how their lives would be different if they had never had seizures, people from the community and epilepsy network samples mentioned similar concerns (see Table 6.3). About a third of each group mentioned improved employment or education; other main concerns for both groups were driving, emotional improvements, and increased energy or activity. Once again a larger proportion of the Rochester sample (20%) than the network sample (11%) said their lives would not have been any different. People in the community sample appeared less concerned overall about the effects of epilepsy on their lives, but among those who were concerned the specific differences mentioned were quite similar to those of the epilepsy network.

Table 6.3: How life would be different without seizures

	Rochester		Epilepsy network	
	(% of 127)	**Rank**	**Rank**	**(% of 357)**
Improved employment (21%) or education (10%)	31	1	1	37
Driving	26	2	3	17
None	20	3	5	11
Emotional improvements	13	4	4	15
Activity or energy increased	13	5	2	22
More freedom, independence	12	6		--
Less health conscious	12	7		--
Fewer problems with family	11	8	6	7
Less sensitive and/or compassionate	9	9		--
Other	7			1
Missing or don't know	2			?

(More than one answer possible)

Summarizing the results of the last three tables, it appears that about one fifth of both community and service referral samples estimate that seizures have fairly or very strong current effects on their lives. The groups described different kinds and levels of current problems, with the sample drawn from the epilepsy network being more often concerned with emotional issues and employment, and the community sample more often concerned with driving and emotional issues. The two groups gave similar descriptions of how they thought their lives would be different if they never had had any seizures--employment, education, driving, emotional stability, and increased energy and activity levels were sought by each group. This indicates that there are specific problems associated with managing epilepsy over time that will be mentioned by both service-based and community-based samples. These types of concerns appear to accompany a history of having epilepsy whether or not one is currently taking medications.

Problems mentioned by Rochester residents

Fewer people in the community sample have current problems, and the sample as a whole therefore makes epilepsy look less handicapping. With that said, however, we must look more closely at the kinds of problems the community sample did mention. Proportionally more of the community sample than the epilepsy network sample said they had no problems or knew of no seizure-related differences in their lives, but this did not mean epilepsy was unimportant for these individuals. About three quarters did describe current problems, with almost one fifth mentioning driving as most important. Driving is an important activity for adults in this country--loss of driving privileges may be more threatening to a community sample than a service sample because losing driving privileges means more to the "high-functioning" people included in the community sample. It links them more inescapably to the epilepsy diagnosis, and creates more potential disruptions (e.g., for the travelling salesperson or executive). A young woman (#122) expressed this clearly when she said: "Driving is the greatest problem I face. If I feel I'm gonna be sick I'm not going to work that day--I'm not gonna chance it. My license is my life. When you're an epileptic and you're tagged you're in trouble."

Information about the behavior of people with seizures is probably a more useful measure of the effects of stigma than is information about whether they say they feel stigmatized. The inherent problem remains that interview studies cannot observe behavior. In contrast to some of the studies reviewed earlier (e.g., Ryan et al. 1980), the Rochester study tried to get around this problem by allowing informants to name the areas in which they perceived problems, as well as asking them specifically about problems related to driving and insurance.

We also asked interviewees how likely they were to tell job interviewers, bosses, and casual acquaintances about their seizures, and what proportion of their family, close friends, close co-workers, and the people they were generally around knew about their seizures. Significant proportions of interviewees said that they thought none or a few of their close friends, co-workers, and general companions knew about their seizures (Table 6.4). If we call these "low disclosure" answers, and sum them together over all seven possible categories, then 35% of 118 respondents gave none or only one "low disclosure" answer, 26% gave two to three such answers, 17% gave four to five, and 22% gave six or seven. In sum, 39% of respondents gave low disclosure answers to four or more of the categories.

TABLE 6.4
Disclosure patterns

	Family	Close friends	Close co-workers	"Those usually around"
Proportion of respondents saying "none" or "a few" of these KNOW about their seizures:	5%	33%	45%	46%

	Boss	Job Interviewer	Casual Acquaintance
Proportion of respondents saying "not at all" or "not too" LIKELY TO TELL these about their seizures:	35%	48%	86%

These numbers are cold estimates, since they convey frequencies without conveying emotion. For example, while only 5% of interviewees said they thought none or a few people in their family knew about their seizures, this meant in some cases that parents had never told children. These decisions were often motivated by perceptions of stigma, as in the following quotation from a woman who had told her children when they were quite small, then had not mentioned it again:

> #242
> We don't talk about it much at home, I think my husband has a problem with it. I don't, but I believe it is either his concern about the legal aspects, or a feeling of a stigma....He didn't even want me to tell the children--he just didn't want (or think it was necessary) for them to know. I thought it would be useful if anything ever came up in their lives later, but I don't know if they even remember, since we don't talk about it.

Decisions to tell sometimes came despite earlier bad experiences. A woman who gave a low disclosure answer to only one of the seven categories nonetheless reported the following experiences:

> #122
> In high school nobody played with me--it was like I wore a tag, 'I'm contaminated,' 'I'm the sick one.' I didn't go to college 'cause I had enough of that in high school. I got a math award, and didn't get it at the graduation like they had said before they knew I won it--I was given it in the hallway.

The disclosure frequency is also misleading in that sometimes epilepsy was revealed despite all efforts to conceal it. A middle-aged woman who said she "would never tell unless forced to," also said she had recently had a public seizure that made further secrecy impossible:

> #256
> They all know now, since the accident [at work] in '84 and that's the problem I'm having. To them--gossipy or I don't know what--it's a form of insanity or retardation. They do tend to pick a little bit. I left a book on it [epilepsy] at work. You can't tell them anything--maybe if they read it they'll learn. When I was younger I didn't tell anybody so maybe I'm facing now what most people [with epilepsy] do when they're younger.

Thus the 61% of respondents who reported three or fewer "low disclosure" answers includes some whose disclosures were made not by choice but by necessity.

Factors associated with problems and secrecy

One of the significant failures of the research literature on stigma and epilepsy is that it too often remains descriptive, presenting statistics and quotations like these about perceived stigma, or debating whether stigma has been over-estimated, without assessing whether perceptions of problems vary with other social or clinical characteristics. I looked at these questions by comparing dichotomized social, demographic, and clinical variables with people's dichotomized answers to the questions about life differences, current problems, effects of seizures, and willingness to disclose seizures to others. To give more detailed estimates of associations I also examined the correlations between non-dichotomous variables. Tables 6.5, 6.6, and 6.7 summarize these cross-tabulations and correlations.

TABLE 6.5
Associations of social outcomes with clinical variables

	Seizure Type	Medications taken in 1985?	Age at Onset	Time since last seizure
Difference in life? (Some vs. none)	N	N	N	Y***
Problem? (Some vs. none)	N	N(.08)	Y*	Y***
Seizure effect? (None or mild vs. fairly or very strong)	N	N	N	Y*
Secrecy about seizures? (Low vs. High)	N	Y*	N	N

(Corrected X^2 probabilities: * p<.05, ***p<.001)

TABLE 6.6
Correlation of selected demographic and clinical variables
(N=127 except where noted)

	(1)	(2)	(3)	(4)	(5)
1) Age (Year)					
2) Years since last seizure	.208*				
3) Duration of epilepsy	.408**	.171			
4) Education (Years)	.011	.283**	-.08		
5) Income (Dollars)	.144	.321**	-.177*	.428**	
6) Secrecy (0-7)	-.040 (118)	.182* (118)	-.066 (118)	.250** (118)	.226* (117)

Significance levels: * p<.05 ** p<.01
(Spearman coefficients used in row 6, Pearson coefficients used elsewhere.)

Clinical factors

Clinically, seizure type was not associated with any of the social outcomes, while seizure recency, medication status, and age at onset were. Proportionally more people with recent seizures reported current problems and differences in their lives caused by epilepsy, and these proportions decreased as time since seizure increased. (Problems were reported by 10% of respondents whose last seizure was below the median time since last seizure, and 42% of those above. Life differences were reported by 97% of the quartile with most recent seizures, 90% of the quartile with less recent seizures, 75% of those still less recent, and 49% of those least recent.) Even though the question about differences attributable to epilepsy did not specify that these differences be current, recency of seizure still affected whether differences were mentioned or not.

This partially answers the question posed earlier in this chapter about whether the effects of epilepsy can be distinguished from the effects of seizures: recency of seizure is associated with contemporary assessments of seizure effects, contemporary assessments of problems, and retrospective assessments of whether the condition made any differences in people's lives. The consistency, strength, and linear increase of the association between reporting differences and recency of seizures implies that the association is real. It may be that this reflects a kind of "cognitive dissonance" (Abelson et al. 1968), where even the retroactive assessment of impact increases with recency of seizures. It seems that the perceived effects of epilepsy are linked to the _appearance_ of seizures, but not linked to _perceptions of the effects_ of seizures.

Although having recent seizures predicted reporting problems or differences, taking medications did not. Taking medications at the time of interview was associated with disclosing the condition: 41% of the 29 people not taking medications, but 67% of the 89 taking medications, were in the high disclosure group. (Nine people had missing information on the disclosure index). It is difficult to sort out all the factors that might be influencing this distribution: perhaps people no longer taking medications do not feel they have any condition to disclose, or perhaps they feel even more strongly that their condition (or former condition) not be revealed. People off medication also had had their most recent seizures longer ago (a mean of 10 years for those off medications, and 6 years for those on medications, F test $p<.002$), so they probably were less likely to have people around them who knew about or had seen their seizures.

Finally, age at onset was another significant clinical factor in whether people reported problems: 86% of those whose seizures began before age 9 reported problems, 75% of those 9 to 22, and 55% of those 22 or older. This finding adds weight to suggestions that child-onset epilepsy is potentially more disturbing to social functioning than adult-onset epilepsy (Bagley 1986, Hermann and Whitman 1986).

Demographic and social factors

Men and women did not respond differently to any of these questions about social outcomes (Table 6.7). Respondent age was related to whether they perceived problems and life differences: 60% of the 69 people aged less than 40, and 40% of the 58 aged 40 or more, reported having current problems, but this was not statistically significant ($p<.07$). Eighty-eight percent of those aged less than 40 and 71% of those aged 40 or more reported life differences they attributed to epilepsy ($p<.02$). Younger people thus appeared more likely to name differences, but this result is confounded by the fact that age and recency of seizures were significantly correlated (R=.21, p<.05), and that recency of seizure was independently associated with reporting life differences. When controlling for time since last seizure, the associations disappear between age and reporting differences or problems.

TABLE 6.7
Associations of social outcomes with demographic variables

	Sex	Age	Income	Education	Occupation
Difference in life? (Some vs. none)	N	Y*	Y**	N	N
Problem? (Some vs. none)	N	N(.07)	N	N	N
Seizure effect? (None or mild vs. fairly or very strong)	N	N	Y*	Y*	Y**
Secrecy about seizures? (Low vs. High)	N	N	N	Y*	N

(Corrected X^2 probabilities: * p<.05, **p<.01)

Socioeconomic differences were associated with perceived stigma and sanctions. Proportionally more people from households with low incomes named differences epilepsy had made in their lives: 97% of those with household incomes below $15,000 named differences, 80% of those with incomes between 15 and 45,000, and 63% of those with incomes above 45,000. Income had a similar association with perceived effects of seizures: 37% of the low income group, 17% of the middle income group, and 14% of the high income group said seizures had a fairly or very strong effect on their lives at present. Income was not associated with secrecy when these variables were dichotomized, but was correlated with secrecy when analyzed as an ordinal variable (Spearman R=.23, p<.02). Though intriguing, these associations also cannot be interpreted causally: high income can reduce the problems posed by chronic illness, but chronic illness can reduce earnings. Deciding which of these alternatives is correct requires longitudinal studies like that in England of Britten et al. (1984, 1986) reviewed earlier. Britten et al. concluded that a diagnosis of epilepsy in childhood did not impede occupational attainment by age 26, which argues against the "downward drift" hypothesis that epilepsy causes downward socioeconomic mobility. (The argument would be stronger were the cases older, but this is one of the problems with longitudinal studies of birth cohorts: the longer the followup the older but fewer the cases.)

Though people with low income were more likely to report problems and life differences, people with low education were not more likely to report problems or life differences attributable to seizures. Education, like income, did appear to influence estimates of seizure effects: half of the 13 without high school degrees, almost 80% of the 80 with high school or some college, and 90% of the 33 with college degrees reported no or mild effects of seizures. Education also influenced nondisclosure of seizures: 28% of those with high school or less were in the high secrecy group, while 48% of those with education beyond high school were in the high secrecy group. (Analyzed as ordinal variables, education and secrecy were significantly correlated [R=.25]).

Since education and income both were associated with secrecy about seizures, it might be assumed that secrecy would also be associated with having higher status occupations. However, high and low secrecy groups were evenly distributed among people in professional, service, and labor occupations, and more than 70% of people from technical and administrative occupations were in the low secrecy group. Occupation was also not associated with reporting problems or life differences, though it was associated with perceived effects of seizures: 97% of those in managerial and professional occupations said seizures had none or mild effects, while 55% of those in production and laborer occupations responded this way.

The Rochester study did provide some objective information about whether people with epilepsy have reduced occupational achievements. Demographic information in Chapter 2 showed that the Rochester interviewees with epilepsy had incomes and educations similar to those of all residents. If Rochester residents with epilepsy differ from other Rochester residents only by virtue of their diagnosis, then the employment profile of employed adults in Rochester should be similar to the profile of employed adults with epilepsy. If epilepsy diminishes occupational achievements, then there should be more residents with epilepsy in lower skill, low status occupations, and fewer in higher skill, high status occupations. Table 6.8 shows that the occupational profiles of the two groups support the idea that epilepsy reduces occupational achievement: 32% of Rochester residents but 22% of those with epilepsy are employed in managerial and professional specialty occupations, and nine percent of Rochester residents but 15% of those with epilepsy are employed as operators, fabricators, and laborers. These differences would be more convincing if the epilepsy sample included all employed adults over age 16 rather than those between 16 and 55. However, there is little reason to believe that adults over 55 would have a profile of occupations so different that it would greatly change these proportions.

Table 6.8

Occupations of all employed Rochester adults aged 16+ in 1980, compared with employed adults with epilepsy aged 16 to 55 in 1980, expressed in percentages.

U.S. Census Occupations:	1980 CENSUS n=31062	1980 CASES n=130[1]
	%	%
Executive, administrative, and managerial	10	7
Professional specialty	22	15
1) Total: Managerial and Professional Specialty	32	22
Technicians and related support	10	11
Sales	9	8
Administrative support, incl. clerical	16	18
2) Total: Technical, Sales, & Administrative Support	35	35
Private household	<1	0
Protective service	<1	1
Other service	15	16
3) Total: Service	17	17
4) Total: Farming, forestry, and fishing	<1	2
5) Total: Precision production, craft, and repair	7	8
Machine operators, assemblers, and inspectors	4	7
Transportation and material moving	2	1
Handlers, equipment cleaners, and laborers	3	7
6) Total: Operators, fabricators, and laborers	9	15

[1] No occupation was listed for 7 Rochester cases, others were housewives (28), students (16), unemployed (10), or under age 16 in 1980 (8).

Distinguishing social stigma from bureaucratic sanctions

While the associations in the Rochester study between socioeconomic status and stigma cannot be interpreted causally, they do suggest that more complex models of social stigma and social sanctions need to be developed: distinguishing between enacted and perceived stigma is a useful first step, since it helps to separate actions taken by people with epilepsy that are based in assumptions about stigma versus experiences with it. Perceived stigma is a broad category, however, and takes too much of its definition from people's internal models of expected behavior. After all, stigma is in the eye of the beheld as much as the beholder: some people who have epilepsy would perceive rejection from a trucker's job as manifesting stigma; others would perceive it as manifesting justifiable caution. It is therefore misleading to measure stigma solely based on people's recall of specific incidents. But it is also wrong to rely on individual perceptions to explain social phenomena: if individual claims of stigma are over-estimated, how then to explain the changing course of legislative sanctions in this country? The "scientific" exclusions of one moment become the baseless prejudices of another, and this process continues through time. Focusing on individual levels of fear, anger, secrecy, and psychopathology, cannot explain why social premiums are still denied to people based on their illness. The next section discusses the kinds of problems respondents reported about driving and insurance restrictions. I then look more closely at the evidence supporting driving restrictions, and suggest that the present level of restrictions can still be seen as overly stringent.

Sanctions described by Rochester residents

Respondents felt Minnesota treated drivers with epilepsy too harshly. One (#157) said, "The State is too hard on people with epilepsy--they say 'If you stub your toe sometimes we ain't gonna let you walk.'" For this person, driving restrictions were a sanction far more devastating than seizures. Another complained about how she was treated by the State, and compared her treatment with that of more dangerous drivers:

> #145
> The police physically came and revoked my license. I forgot to send in the safety form, or we were moving a lot and I didn't get it. They hunted me down and took it away, right in front of my kids, like I was some kind of criminal! And that was back in the days when there were drunk drivers all over the place.

Legislative sanctions like driving restrictions increase the level of social interference from the disorder and cause a person with epilepsy to face a broader exposure to stigma. Sanctions are therefore particularly important to people with epilepsy who are "in the closet" (Schneider and Conrad 1980), and to those whose epilepsy is mild: they magnify the stigmatizing side of the illness, and its potential threat to everyday life. Goffman explains this by saying that a person's "particular stigmatizing attributes do not determine the nature of the two roles, normal and stigmatized, merely the frequency of his playing a particular one of them" (1963:138). People with less severe cases of epilepsy may find most onerous those social sanctions that cause them to play the role of "epileptic" most frequently: e.g., loss of driving privileges, or a recurrent need to justify maintaining them. Since the need to drive is so pervasive in our society, and the ability so taken for granted, inability to drive becomes a more important handicap for these people than seizures.

Table 6.9 presents information about how Rochester residents viewed Minnesota's restrictions on driving eligibility: more than one quarter of respondents were not driving at the time of the interview. Among those who were driving, 40% said they were not reporting their seizures to the State, or had stopped reporting after having what they thought were excessive problems or restrictions imposed upon them by the State. (Under Minnesota law, a person who has had a second seizure must surrender his license for one year, and must report additional seizures annually to the State for three years afterward. Some respondents said the State required them to report annually for as long as they lived in the State.) About one third of present drivers said they had had their licenses revoked at some point in the past, or were annoyed by the procedures established for obtaining licenses following seizures. Almost 20% of present drivers had stopped driving in the past because of seizures, and another 18% of drivers said they had no problems.

TABLE 6.9
Problems with Driving Eligibility

(35 of 127 (28%) were not driving at the time of the interview)

Among 92 present drivers

37 (40%) never reported seizures to the State, or stopped reporting

33 (36%) had had licenses revoked or were annoyed by reporting requirements

17 (18%) had stopped driving in the past because of seizures

17 (18%) said they had had no problems
(Respondents could give more than one response)

Insurance was another issue for people with epilepsy (Table 6.10). Almost one fifth of respondents said they had had problems obtaining health or life insurance: their applications had been rejected or approved at higher premiums, they had had to lie about their epilepsy in order to obtain insurance, or their applications had been approved only after long delays and disagreements. Though these proportions are not small, they are probably underestimates of the problems encountered by most people with epilepsy, since so many people in Rochester are covered either directly or indirectly through some Mayo insurance plan. Some of those whose insurance policies predated the onset of their epilepsy intimated that they had never informed the company about their seizures; others implied they carried their coverage under someone else's policy to avoid potential problems. These people did not report problems obtaining insurance, but they had adopted strategies that avoided potential problems.

TABLE 6.10
Problems with Insurance

	Health Insurance		Life Insurance		Car Insurance	
	N	(%)	N	(%)	N	(%)
Problems obtaining:	23	(18)	26	(20)	10	(8)
No coverage:	7	(5)	18	(14)	30 (Not driving)	(24)
Other coverage or coverage predates:	22	(17)	11	(9)	9	(7)
No problems:	75	(59)	72	(57)	78	(61)

Summary

These figures and quotes from the Rochester sample suggest that epilepsy poses problems even for this group of well-educated whites with high incomes. Those who say their seizures have mild contemporary effects still face the restrictions posed by insurance companies and motor vehicle departments; those whose seizures are recent or poorly controlled face more encompassing problems like job discrimination, emotional problems, lifestyle restrictions, and the like. Even in a medically sophisticated community like Rochester, where one quarter of households contain someone who works in a health facility, many people with epilepsy are reluctant to make their condition known. It is likely that levels of stigma, misunderstanding, and discrimination would be higher in areas with less exposure to medicine, and that the kinds of adjustment problems found among Rochester residents would be compounded by minority status, urban residence, or low income or education.

Given the importance of bureaucratic sanctions to these respondents, it is important to examine the scientific foundations of these sanctions, to see whether they are enduring remnants of past stigma and misunderstanding, or whether they reflect the most rational and enlightened policies that can be fashioned today. The next section reviews some of the evidence about driving risks for people with epilepsy, as well as the variations in state regulations designed to control these risks. This review is illustrative, since a similar review could be done of evidence surrounding employment performance, insurance risks, and other areas where bureaucratic sanctions are found.

DRIVING RESTRICTIONS: PUBLIC GOOD OR PRIVATE HARM?

Driving is an essential part of American culture. Driving is important to us not only as a means of transportation, but for the images it conveys: freedom to move and to express ourselves; freedom from monotony. Not driving can bring real constraints: losing a job, or not being able to take one in the first place. Losing a license also raises issues like who you tell, how you explain it or avoid telling, and how much it will cost in time and money to get the license back. These are some of the reasons driving was so often mentioned as a problem by Rochester respondents with epilepsy.

There are clinical and administrative reasons for restricting drivers licenses for people who have had seizures. These restrictions are thought to increase the safety of the public, but little is known about the effects of such policies. Restricting driving for people with epilepsy is a struggle between public good and private harm: the public good may be served by taking dangerous drivers off the road, but there are few figures to back up that perception. Restrictive policies are public, but their impact is private.

To decide whether present levels of driving sanctions are valid, the following questions should be answered: 1) Do people with seizure disorders have higher accident rates than normal controls? 2) Do they have higher accident rates than people with other illnesses that carry drivers license restrictions? Are they treated similarly to those other groups under state law? 3) What kinds of accidents do they have: serious ones involving fatalities and major injuries, or minor ones involving property damage? 4) What proportion of accidents can be attributed to seizures rather than to driving conditions, driving habits, alcohol, and the like? 5) Given the prevalence of epilepsy and the accident risks for people in this group, what proportion and number of accidents might be attributable to people with epilepsy? 6) Is there general agreement about how the scientific data on accident risk should be turned into legislation? That is, are sanctions similar from state to state or do they differ considerably?

Sporadic and unpredictable loss of consciousness, especially when it can happen in a split second, is an obvious risk factor for accidents while driving. Many of the figures supporting tight restrictions came from studies in the 1960s showing higher accident rates among drivers with epilepsy compared to groups without epilepsy. The following table (6.11) gives results from four studies that measured exposure to accidents differently. The ratios of accidents among cases compared with control or comparison groups are between 1.3 and 2. However, the ratio of the most recent study was not significantly different from 1, suggesting that there is some uncertainty in these conclusions.

Table 6.11
RATIO OF ACCIDENTS AMONG DRIVERS WITH EPILEPSY
COMPARED TO DRIVERS WITHOUT EPILEPSY

	Proportion of male drivers with registered accidents		
	Epilepsy Cases	Age-matched controls	Ratio
Hormia 1961 (Finland)	.42	.31	1.38

	Three year accident rate per million miles		
	445 Epilepsy Cases	1646 Age-adjusted comparison	Ratio
Waller 1965 (California)	16.0	8.2	1.95

	Seven year average for accidents per 100 drivers		
	1169 Epilepsy Cases	Sex and Age-adjusted population (1.6 million)	Ratio
Crancer and McMurray 1968 (Washington)	41.4	31.1	1.33

	Proportion of drivers having one or more collisions		
	108 Epilepsy Cases	108 Matched Controls	Ratio
Paulsrude and McMurray 1978 (Washington)	.065	.046	1.4 (Not significant)

Even if there is an increased risk of auto accidents among people with seizure disorders, other illnesses appear to place a driver at equivalent risk of losing control of an automobile. California Motor Vehicle records described episodes of loss of consciousness or conscious control among three quarters of a group of drivers with diabetes, two thirds of those with cardiovascular disease, one third with alcoholism and other miscellaneous conditions, and one quarter with certain kinds of mental illness (Waller 1965:1416). Some of the studies of accident risk have compared rates within this range of illnesses, and it turns out that although the rate of automobile accidents for people with seizures is elevated, it is not significantly higher than that among people with diabetes, and by some measures also not higher than that for cerebrovascular diseases (see tables 6.12 and 6.13).

TABLE 6.12
THREE YEAR ACCIDENT RATES PER MILLION MILES
FOR DRIVERS WITH VARIOUS HEALTH PROBLEMS
State of California, 1963

Condition	Cases	Age-adjusted comparison	Ratio
Mental Illness	15.3	7.2	2.1
Epilepsy	16.0	8.2	2.0
Diabetes	15.5	8.7	1.8
Alcoholism	11.3	6.8	1.7
Cerebrovascular disease	14.6	9.0	1.6

(adapted from Waller 1965:1417)

TABLE 6.13

AVERAGE ACCIDENTS PER 100 DRIVERS WITH VARIOUS HEALTH PROBLEMS
State of Washington, January 1961 to October 1967

Condition	Observed	Age/Sex-adjusted Population	Ratio (O/P)
Fainting	49.4	27.0	1.8
Epilepsy	41.4	31.1	1.3
Other	31.8	26.3	1.2
Diabetes	31.4	26.5	1.2
Cardiovascular	25.9	25.3	1.0
Vision	25.4	25.5	1.0

(Other includes psychological and neurological disorders, stroke, hypertension, alcoholism, drug addiction, and miscellaneous.)
(adapted from Crancer and McMurray 1968:274)

People with diabetes or cerebrovascular problems usually are treated less harshly for driving eligibility than are people with epilepsy. In Florida, where epilepsy causes a driver to be denied a license until proof of seizure control is obtained, diabetes causes a license to be reviewed almost always <u>after</u> an accident report has implicated hypoglycemia (Lasche 1985). In Minnesota, all members of the driving review commission are neurologists. They report seeing few if any people with diabetes (Leppik 1986, personal communication), though it is covered under the same statute that affects epilepsy. Differential treatment of people with diabetes and epilepsy is also seen in figures describing the proportion of people who initially had their licenses revoked by the California Motor Vehicles Department: these figures (Table 6.14) suggest that people with epilepsy are perceived to pose a driving hazard similar to that of people who use drugs or alcohol, while those with diabetes or cardiovascular disease are treated less harshly.

TABLE 6.14
Initial action taken by California Department of Motor Vehicles

Medical Category	Percent of People in Category whose Licenses were Revoked
Drug Usage	68%
Epilepsy	61
Alcoholism	54
Mental Illness	46
Cardiovascular Disease	39
Miscellaneous	31
Diabetes	26

(from Waller 1965:1418)

What kind of accidents would be prevented if nobody who had epilepsy drove? One of the few studies on this topic showed that accidents involving people with epilepsy involved fewer serious injuries, and more slight physical injuries, than the "average traffic accident" (Van der Lugt 1975:748). Three quarters of all the accidents in the Netherlands were caused by collisions between two or more vehicles, while less than one quarter of accidents among people with epilepsy were caused by collisions of this type. People with epilepsy tended to drive off the road or hit immovable objects. And finally, half of the accidents among people with epilepsy happened outside urban areas, whereas one fifth of all other accidents happened outside urban areas. The authors suggest that the alertness and attention required for driving in urban areas help to suppress seizures. Drivers with epilepsy may have fewer seizures while driving in urban areas, or they may drive more carefully in urban areas.

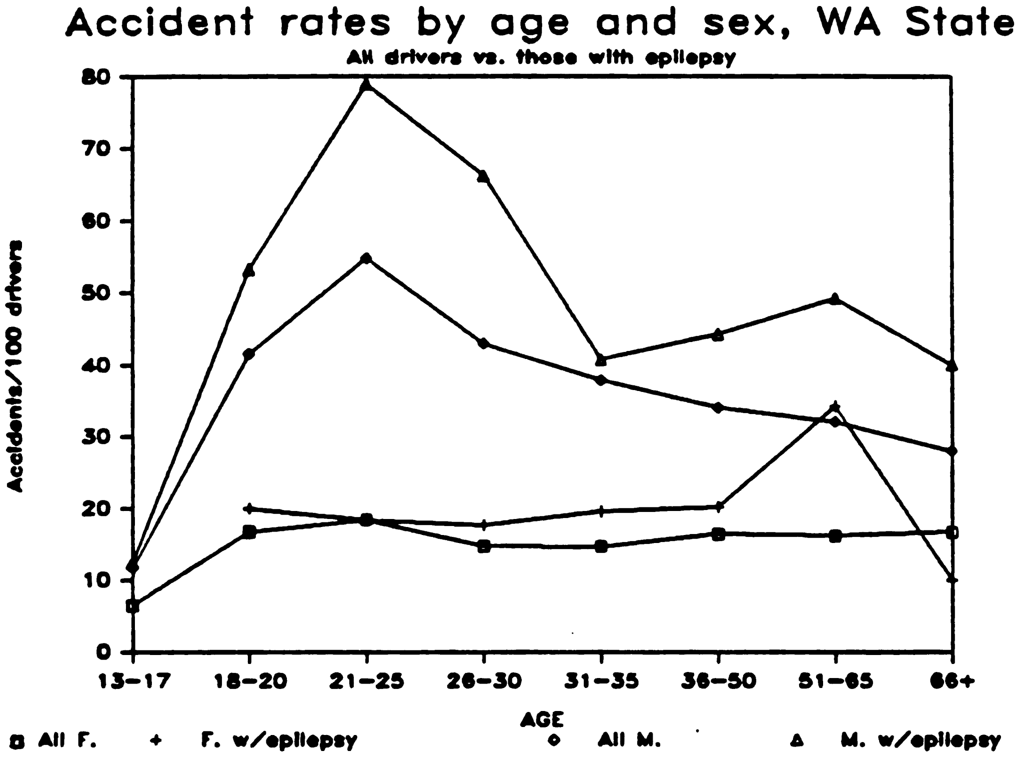
We expect medical and public health recommendations to be based on statistical concepts of risk rather than emotional responses to particular accidents, yet scientific rationales may be suspended when epilepsy is involved. A National Transportation Safety Board document (#NTSB86-916202) described a 1985 North Carolina accident involving two trucks, a schoolbus, and a car. Seven people died and 25 were injured in the accident, caused by a truck driver who crossed over a highway centerline. The driver had a history of seizures, with none since 1980, had low levels of phenobarbital in his blood, and had slept only about one and a half hours in the 36 hours before the accident. Fatigue and stress were clearly present, but the board concluded it "could not rule out" the possibility of a seizure. The NTSB made eight national policy recommendations after the accident: four of these concerned further restrictions for drivers with epilepsy, including mandatory reporting in all states, and four concerned design modifications for school bus joints. Thus epilepsy became the _de facto_ cause of the accident, and the NTSB recommended national legislation based on one possible cause of one particular tragedy.

Looking at this another way, we know that drivers will have accidents whether or not they have any chronic illnesses. In fact, alcohol-impaired drivers are thought to cause between a quarter and a third of _all_ accidents causing serious injuries. Nobody would argue that all traffic accidents that happen to people who have epilepsy are by definition caused by a seizure: cars stop short, sunlight glares on windshields, children chase a ball into the street. What proportion of the accidents that _do_ happen to people with epilepsy appear to have been caused by a seizure? A German study (Janz 1967) found that only about 20% of accidents among people with epilepsy were caused by a seizure.

The importance of factors like age and sex, in addition to diagnosis, can be seen in the following three graphs (Figures 6.1, 6.2, and 6.3). These were constructed from figures published in the Washington study (Crancer and McMurray 1968). They show that males have higher accident

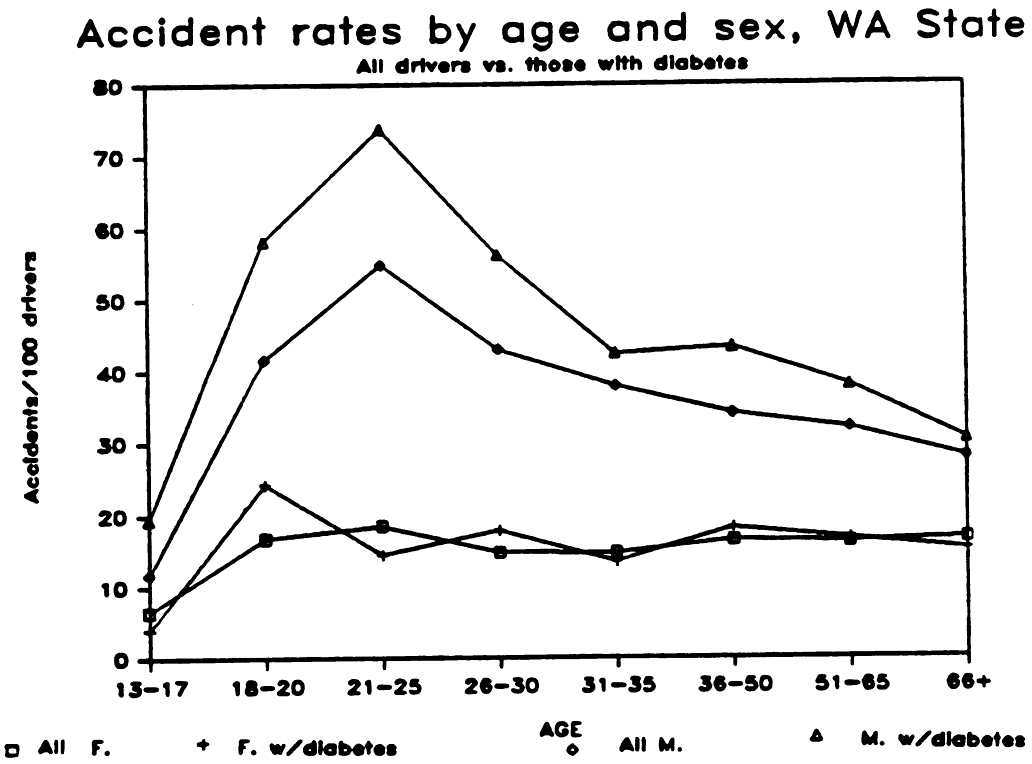
rates than females, that the young have more accidents than the old, and that the accident profiles of people with diabetes and epilepsy are quite similar.

FIGURE 6.1



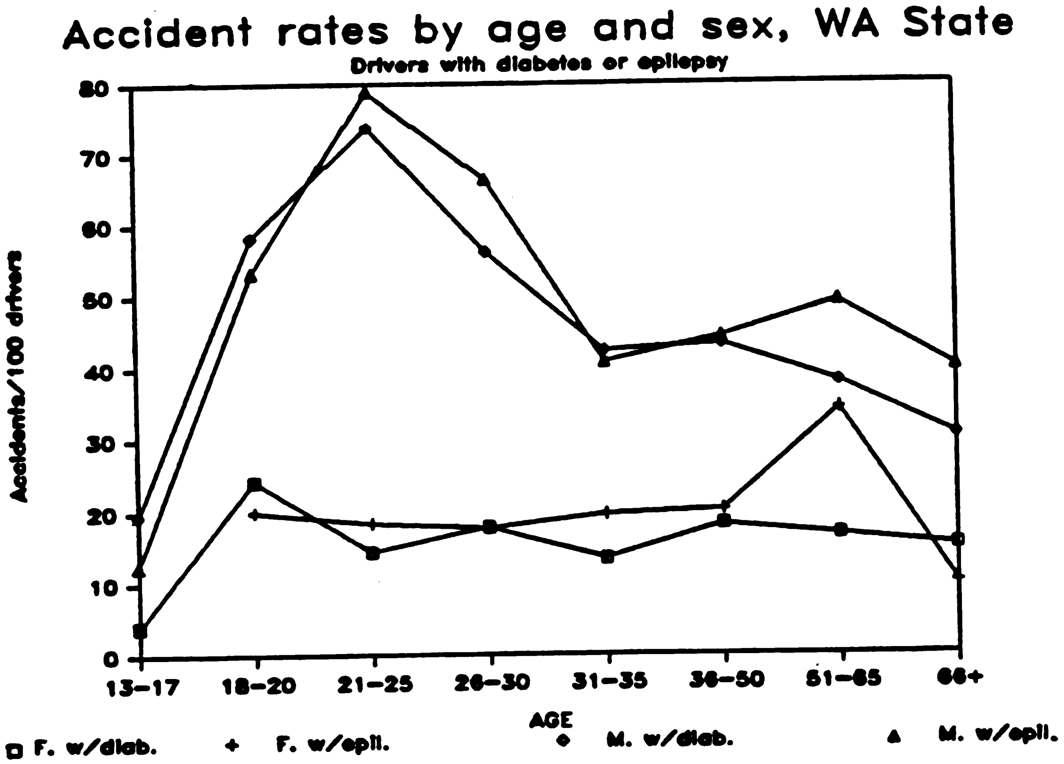
(Adapted from Crancer and McMurray 1968)

FIGURE 6.2



(Adapted from Crancer and McMurray 1968)

FIGURE 6.3



(Adapted from Crancer and McMurray 1968)

What proportion of all traffic accidents are attributable to seizures? This is an important estimate, for it suggests the extent of public benefit obtained by limiting licenses for drivers with epilepsy. Most studies say that between 1 and 3 of every 10,000 accidents are attributable to epilepsy (Herner et al. 1966, 2.7 per 10,000 accidents in England; Grattan and Jeffcoate 1968, 2.9 per 10,000 in England; van der Lugt 1975:749, 1 per 10,000 in the Netherlands). These figures do exclude people with epilepsy who have never identified themselves to license authorities, so they may underestimate the risk: misclassification of people with epilepsy as people without it will deflate the accident rate for the epilepsy group and inflate it for the non-epilepsy group.

Assuming these proportions are correct, how do they translate into numbers? Minnesota had over 107,000 traffic accidents in 1985 (MN Department of Public Safety: 1985 Crash Facts Book). If the rate of accidents caused by epilepsy is as high as 3 per 10,000, we are talking about 32 accidents per year in the state. If it is as low as 1 per 10,000, we are talking about 11 accidents per year in the state. The discussion of relative risks needs to keep these totals in mind: if the published figures are correct, 11 to 32 traffic accidents are attributable to seizures in Minnesota each year. If we take out the 10% of unpreventable accidents that happen at the time of a person's <u>first</u> seizure, then 10 to 30 additional accidents per year may be prevented by imposing driving restrictions on Minnesota residents with epilepsy. People with epilepsy should be prohibited from driving only because the legislature decides that the public benefits of preventing 10 to 30 additional accidents per year outweigh the costs to Minnesota's 16,000 people with epilepsy of driving age.

Current laws restricting drivers with epilepsy are written and administered inconsistently both within and between states, and this inconsistency also raises questions about how the scientific evidence is being interpreted. Most states prefer blanket regulations to individual case assessments, but their laws vary (see Table 6.15). At present all states give driver's licenses to persons with epilepsy who have achieved 'control' of their seizures, but they define control in many different ways, ranging from a physician's assessment (ten states) to mandatory post-seizure license suspensions for one and a half to two years (three states). Some states do not suspend licenses following seizures caused by regimen changes, but do suspend licenses following seizures caused by poor compliance--there are thus acceptable and unacceptable seizures.

States also vary in the frequency of clinical examinations required after a license has been re-issued: the range here is from updates only on license renewal, to annual updates for ten years after a seizure. Six states require physicians to report their patients with epilepsy to the motor vehicle department.

Table 6.15
Variations in State Epilepsy Licensing Regulations
(adapted from Epilepsy Foundation of America 1986)

State	Required seizure-free period for licensing	Frequency of clinical updates
Tennessee	None	Medical Review Board discretion
Kentucky	3 months	Medical Advisory Board discretion
Iowa	6 months (less if nocturnal)	Every 2 years
Minnesota	12 months	Annual (3 years) Then every 4 years
Vermont	2 years (6 mo. with MD recommendation)	Every 6 months until 2 years seizure-free

The comments of Rochester residents

My respondents had concerns about driving, but they also objected to the way they were treated by the bureaucrats in the State driver's license division. Some complained of what they called arbitrary treatment compared to others they knew who had epilepsy. Others complained about unequal treatment compared to drunk drivers, and people with diabetes or heart conditions. In fact their concerns raised many of the same issues that the epidemiologic data raise. Most basically the people I spoke with saw driver's license restrictions not as a means to protect the public safety, but as an added hindrance to lives already burdened with chronic illness. They saw driving restrictions as an important visible marker of a medical diagnosis many preferred to hide.

One woman described what happened when she did not send in her medical form to the Department of Public Safety:

> #145
> "The police physically came and revoked my license. I forgot to send in the safety form, or we were moving a lot and I didn't get it. They hunted me down and took it away, right in front of my kids, like I was some kind of criminal! And that was back in the days when there were drunk drivers all over the place."

Another complained about the arbitrary enforcement of regulations:

> #146
> "I moved to Minnesota in '67 and started having problems then--I needed a doctor's statement saying I hadn't had any seizures in 2 years, and I had to get it notarized. All the drunks on the highway--nobody did anything about them. People having heart attacks--nobody regulates and monitors them.... I had to recertify every 2 years and it was an inconvenience. I could see doing it if I'd had a seizure within 2 years, but I'd had no seizures for 15 years."

This person's last seizure was listed as 1952, 15 years before her move to Minnesota. If in fact she did have to recertify every two years, the Minnesota law plainly was not being enforced as intended or written, since it requires annual reports for three years, then reports at license renewal.

Finally, another mentioned physician arbitrariness, and the economic costs of losing a driver's license. This comment again raises the problematic role of the physician as an enforcer of social policies:

> #147
> "My doctor wouldn't sign the form even after a year--he thought nobody who'd had a seizure should drive, even if you're under control. Lots of people who are behind the wheel of a car are too dangerous, and I don't drive a lot anyway--I respect it. But to take cabs back and forth to work--I can't afford to do that."

Summary

Managing epilepsy involves far more than taking medications and attending medical appointments. Yet previous attempts to describe the problems faced by people who have epilepsy have used research strategies that are most likely to make epilepsy look particularly devastating. These differences are visible when the responses of Rochester residents are compared to the responses of people sampled through a network of service providers. Compared to the network study, more people in the community study reported no problems (26% vs. 3%) and no differences in their lives caused by epilepsy (20% vs. 11%). However, among those who did mention problems, people from the community and epilepsy network samples voiced similar concerns: people from the network sample mentioned emotional and job-related problems while people from the community sample mentioned driving and emotional problems. People from the network sample mentioned quality of life differences in the areas of employment, education, and diminished activity or energy levels; those from the community also mentioned employment and education, and again mentioned driving. Epilepsy in the United States thus appears to present a coherent series of important social and emotional problems, though the prevalence of these problems in a middle class white community is not as great as has previously been suggested.

Seizure type, sex, and age were not associated with mentioning contemporary problems or life differences, or with the level of secrecy about the condition. Clinical factors were associated with some of these outcomes, including recency of seizure, age at onset, and whether medications were still being taken, as were income, education, and occupation. The cross-sectional design used in this study cannot show whether epilepsy leads to lower socioeconomic achievements, or whether people with more socioeconomic resources are protected from epilepsy's potential to intere.

Rochester residents face the problem of whether to disclose the existence of an episodic condition. Their responses also reveal the burden that bureaucratic sanctions add to individual misunderstanding and discrimination: both driver's license regulations and insurance restrictions caused problems for respondents.

Reviewing the evidence about driving risks for people who have epilepsy reveals that people with epilepsy have been treated more harshly relative to other drivers with similar health problems. It also reveals uncertainties and inconsistencies about how the evidence on accident risk has been turned into legislation. Many of the present laws appear to do more private harm than they do public good.

CHAPTER SEVEN: CONCLUSIONS

Anthropologists can play a valuable role in "unpacking" the variables used in epidemiological and sociomedical research. Knowledge of cross-cultural variability and intra-cultural diversity can be used to conceptualize the meanings and best measurements for variables like race, ethnicity, social class, social networks, and--as I have argued here--compliance with treatment regimens. At the same time that anthropologists can contribute to the research methods and theoretical controversies of other disciplines, so they reach out to use the concepts and methods devised by other disciplines (Trostle 1986a, 1986b). The purposes for which the method was developed may differ from those for which the method is subsequently used, but how valid the method is depends more on whether its results are intelligible than whether its application is familiar.

Epidemiological sampling methods were used in this study to improve the generalizability of the study's results. Traditional anthropological methods of long-term observation originally raised my interest in how people who have epilepsy manage their condition, but these anthropological methods could not be used to answer my subsequent questions. I wanted to know whether these beliefs and behaviors were common, and whether they were associated with other factors. These questions required larger numbers, greater control over the sources of interviewees, and different ascertainment methods.

The problem with combining anthropological and epidemiological methods is that one risks having the status of a child of divorced parents. You cannot live with both with both at once, your communication with each of them is difficult, and strained by your ongoing relationship with the other, and they rarely communicate. The results of studies combining anthropological and epidemiological methods and theories look incomplete from the perspective of either discipline. From one side, no risk ratios; from the other, insufficient attention to the phenomenological significance of events.

Chapters One and Two explored some of the epidemiological and clinical aspects of the study of epilepsy. I contrasted the etiological theories of patients and physicians, and used epidemiologic concepts of bias to assess the generalizability of my interview results. This assessment showed that my results were generalizeable to the larger group of adults with epilepsy in Rochester, but that they were biased by the absence of people who had emigrated from Rochester between 1980 and the interview in 1985-86. It appears that these results can be generalized to other white middle class urban communities in the United States, but that great care should be taken in generalizing to minority populations, other age groups, or large metropolitan populations.

Chapter Three left the topic of epilepsy in Rochester to critique the clinical concept of "compliance" with therapeutic regimens. This analysis is anthropological and sociological in that it was concerned with power, ideology, and belief systems, but it was also grounded partly in epidemiological concerns: Kerr White's model of the "ecology of medical care" presented in Chapter One is essentially an epidemiologic conception of health service utilization, yet it also provides a natural link to social science concerns with varieties of symptom definition and health-seeking behavior. The goal of Chapter Three was to critically examine the concept of compliance and to uncover its connections to the natural history of managing chronic illness. Anthropologists can contribute to the compliance literature by emphasizing the <u>variety</u> of resources used by the afflicted in their search for health, and the relative *unimportance* of the patient role when compared with roles as parent, household head, employee, or neighbor. The link between compliance and the natural history of managing illness is that when people are *not* doing what physicians tell them to, they commonly *are* doing what they think is right for them, which means exploring whatever they feel may stop or reduce their seizures.

Chapter Four showed that white middle class people with epilepsy commonly have adapted their treatment regimens to fit their own needs, beliefs, and life circumstances. Many have explored other sources of care in addition to their physician, though they usually have done so while getting care from a physician. With so many people self-regulating their regimens and using alternatives (diet, vitamins, stress reduction) to biomedical treatment, we might better ask why people *do* follow a physician's prescription rather than why they do not.

In order to work more effectively within patients' agendas, health care personnel need to know a few specific facts about therapeutics. First, *how much* variability in medication consumption can be tolerated while maintaining seizure control, so that the natural course of taking medications is not compared with some unattainable and unnecessary gold standard of perfect compliance. Second, *which* side effects are most troublesome for patients, and which ones most desired? Which ones are likely to cause medications to be decreased, and which to cause increases? Third and most important, *when* can medications safely be discontinued for people who have had multiple seizures? The tendency for physicians is to keep people on medications, but the tendency for people on medications is to want to get off them.

There are many unanswered questions for future research on the topic of compliance, any of which could also be studied specifically for epilepsy. What does the concept of compliance mean when applied to indigenous therapies used in the non-industrialized world? Does concern for compliance vary with the professional organizations of physicians in different countries? How much of the variability in medication consumption is particular to aspects of epilepsy, and how much generalizable to other chronic illnesses?

Chapter Five showed that epilepsy exerts a social influence far out of proportion to the duration or damage caused by seizures. It is burdened by a long history of misunderstanding extending into the present. People who have seizures, who had seizures, and who take medication to prevent seizures, all deal to varying degrees with this legacy. Contrary to claims that epilepsy conveys an exalted status in some cultures, it appears rather that epilepsy conveys a stigmatized status in all cultures. People known to have epilepsy are devalued, their condition maligned, misunderstood, or set apart. This stigmatized status may be reduced for some who become prophets, diviners, and spiritual healers, but entry into these roles is rare for people with epilepsy. In some cultures epilepsy, while stigmatized, is nonetheless thought to convey compensating attributes like creativity or genius. These beliefs convey an extra burden, a double stigma, to the majority of people with epilepsy who are no more creative nor intelligent than those around them.

Convulsions are sudden, obvious, and disordered behaviors that provoke, and even demand, responses from others. Stigma produces a variety of responses: families get over-protective; strangers show fear and revulsion; and society sets up a series of rules that attempt to limit the perceived dangers. Individuals who have seizures may themselves be afraid, self-protective, inhibited. Even if they have positive or neutral responses to their diagnosis, they must prepare to manage the responses of others.

Chapter Six showed that a large proportion of a community-based sample of adults with epilepsy felt their condition had led to important changes in their lives, and felt they had experienced problems derived from the organized sanctions our society imposes on people who have epilepsy. This contradicts the view of some researchers that the stigma perceived by people who have epilepsy in the modern industrialized world is largely self-generated, based more in a socialized expectation of negative responses than in experience with negative responses. The effects of seizures can be distinguished from the effects of epilepsy, but it appears that recency of seizure itself affects people's judgments that their epilepsy had caused problems. Socioeconomic differences also affect perceptions of problems, though it is impossible to decide from a cross-sectional survey whether these problems themselves cause lower socioeconomic status, or whether high socioeconomic status insulates people from epilepsy-related problems.

Epilepsy as a cultural diagnosis is commonly applied only to convulsions, and then only to those convulsions that are not culturally appropriate and predictable responses to death of a family member, emotional shock, spirit possession, and other events that are culturally significant. Although neurologists categorize seizures according to brain function, looking at where electrical activity begins and how far it spreads, the public categorizes seizures according to visibility. It is ironic that physicians rely on the word "seizure" to avoid the charged meanings conveyed by the word "epilepsy," but they still convey the ancient understanding that convulsions come when one is "seized" by spirits:

> And behold, a man from the crowd cried, "Teacher, I beg you to look upon my son, for he is my only child; and behold, a spirit seizes him, and he suddenly cries out; it convulses him till he foams, and shatters him, and will hardly leave him..." ...Jesus rebuked the unclean spirit, and healed the boy, and gave him back to his father. (Luke 9:37-43, Revised Standard Version of the Bible)

People with epilepsy from a wealthy and medically well-served area like Rochester still have a hard time managing the social ramifications of their diagnosis. In this group organized sanctions were a more onerous part of the condition than were everyday encounters with individual misunderstanding. Driving restrictions were the most important issue for Rochester residents since they were the most important remaining sign and precipitant of social stigma, and they directly affected employment, earnings, mobility, and many other aspects of day-to-day affairs.

Early pressures to deny driving privileges to people with epilepsy were part of a general social prejudice against people with the condition, buttressed by conventional medical wisdom. Policymakers continue to confront the dilemma of whether to relax or tighten regulations amid conflicting medical advice. More attention needs to be paid to the available epidemiologic statistics on risks of seizure recurrence, and better studies need to be conducted. Professionals and legislators need to get accurate risk estimates rather than emotional responses to individual tragedies. They must also decide what levels of risk are acceptable. The voices of those affected by the legislation must be taken into account, since suspension of driving privileges appears to be the most important sign and cause of social stigma toward people with epilepsy today.

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APPENDIX 1

Letter of invitation: Version 1

Mayo Clinic Rochester, Minnesota 55905 Telephone 507 284-2511

Department of Medical Statistics
and Epidemiology

Dear:

We are undertaking a study of feelings about health and use of health services among people who have lived in Rochester, Minnesota, and your name was among those selected as someone who would provide important information.

If your agree to be contacted, within the next two weeks you will receive a call from a member of the project staff who will discuss this project with you and answer your questions about it. He will ask whether you are willing to take part in an hour-long confidential interview, to be held either at your home or at the Mayo Clinic at a time that is convenient for you.

You are under no obligation to participate in this interview. If you do not wish to be called, you may use the enclosed postage-paid envelope to return this form advising us that you do not want further contact with this project. Your decision to participate or not to participate will not affect any care you receive at the Mayo Clinic or its associated hospitals. However, the more people who participate, the more accurate our picture of the community will be.

The interview will be confidential: no names, addresses, or identifying information will be released to anyone outside Mayo Foundation and the interview results will not be placed in your Mayo Clinic record. Only the project staff will have access to the interview data, which will be published only as statistical summaries.

If the individual named above no longer reside in southeastern Minnesota, please check that box on the enclosed form and return it in the enclosed postage-paid envelope.

Thank you for your help.

Sincerely yours,

James Trostle, MA, MPH
Department of Medical Statistics
and Epidemiology

Frank W. Sharbrough, M.D.
Department of Neurology

APPENDIX 2

Letter of invitation: Version 2

Mayo Clinic
Rochester, Minnesota 55905 Telephone 507 284-2511

Department of Medical Statistics
and Epidemiology

Dear

We are doing a study to find out more about the nonmedical aspects of illness and treatment. In health care today what happens outside of the doctor's office is just as important as what happens inside it. Illnesses and medical treatment can affect work, driving, insurance, and other parts of day-to-day living. We are asking people in our community to help us by letting us learn from their opinions and experiences. This information will be used to improve medical and social services in Rochester and elsewhere.

Your name was selected from a list of people with particular medical conditions who have lived in Rochester, Minnesota. For our results to be reliable, it is important that as many people as possible in our sample participate in the study. The study involves taking part in an hour-long interview and completing, on your own, a true/false questionnaire. The interview can take place at your convenience--in your own home, at the Mayo Clinic, or over the telephone.

The information gained from your interview and true/false questionnaire will be confidential. Your name and address will be separated from your answers, and your answers will not be placed in your Mayo Clinic record. Only our project staff will have access to this information and it will be published only as statistical summaries.

The results of the research will be made available to the Mayo Clinic and other health-related organizations in the area. Results will also be published in medical journals. You may receive a summary of the results by calling Dr. F.W. Sharbrough's office (284-3334) in the spring or summer of 1986.

Please understand that your medical care at Mayo Clinic will not be affected by whether or not you participate. Specifically, your care will not be jeopardized by your failure to participate.

We hope that you will be willing to be involved in this study. Please place a check mark opposite one of the four statements on the next page and return that page to us in the enclosed, stamped envelope.

Thank you for your help.

Sincerely,

James Trostle

James A. Trostle, MA, MPH
Department of Medical Statistics
and Epidemiology

Frank W. Sharbrough, MD

Frank W. Sharbrough, MD
Department of Neurology

APPENDIX 3

Record Abstract Form

Investigators: Mr. Trostle, Dr. Sharbrough
Statistician: Dr. O'Brien

Study number 3252
Card number 01
October 14, 1985

COMPLIANCE AND EPILEPSY

Name ______________________, ______________________, ______________________
Last First Maiden

Column	Item	
1-7	_ - _ _ _ - _ _ _	Mayo Clinic number
8-14	_ _ _ _ _ _ _	OMG or outside source number
15-20	_ _ - _ _ - _ _	Date of last follow-up (MM/DD/YY)
21-23	_ _ _	Last follow-up status (ICD 000 = alive)
24-26	_ _ _	U.S. census code for occupation in 1/1/80 (If <18 years old, highest parental occupation)
		Address at last follow-up ______________________ ______________________ ______________________
		Phone at last follow-up ______________ ('85 phone?_____)
27-29	_ _ - _	New seizure classification since 1/1/80? (Code new classification or "00 0")
30-35	_ _ - _ _ - _ _	Date of last seizure (MM/DD/YY)
36-41	_ _ - _ _ - _ _	Date of last medication (MM/DD/YY)
42-47	_ _ - _ _ - _ _	Since 1/1/80, date of remission without seizures
48-53	_ _ - _ _ - _ _	Since 1/1/80, date of remission without medications
54-59	_ _ - _ _ - _ _	Since 1/1/80, date of relapse
60-65	_ _ - _ _ - _ _	Date of last neurology or seizure-related visit
66-67	_	Within 12 months of above date, number of neurology or other seizure-related appointments
68	_	Within 12 months of above date, number of missed neurology or seizure-related appointments
69-70	_ _	Within 5 years of above date, total number of neurology or other seizure-related appointments # Consults _____ # EEG's _____ # Levels _____ # Misc. _____
71	_	Within 5 years of above date, number of missed neurology or seizure-related appointments
74-75	0 1	Card number
76	1	Section number
77-80	3 2 5 2	Study number

Investigators: Mr. Trostle, Dr. Sharbrough
Statistician: Dr. O'Brien

Study number 3252
Card number 02
October 14, 1985

COMPLIANCE AND EPILEPSY

Column	Item	
1-7	_ - _ _ _ - _ _ _	Mayo Clinic number
8	_	Since 1/1/75, total number of noncompliance notations
	Newer note text:	________________
		________________
9-12	_ _ - _ _	Date (MM/YY) ________________
		Location: ________ Author: ________
	Older note text:	________________
		________________
13-16	_ _ - _ _	Date (MM/YY) ________________
		Location: ________ Author: ________
17-18	_ _	#1 Medication Code (see protocol)
19-22	_ _ _ . _	Most recent plasma level of medication #1 (Mcg/Ml)
23-28	_ _ - _ _ - _ _	Date of plasma level (MM/DD/YY)
29-32	_ _ _ _	Dose of medication #1 (mg/day prescribed)
33-35	_ _ _	Weight (in kilograms, [lbs. X .45]) on above date
36-37	_ _	#2 Medication Code
38-41	_ _ _ . _	Most recent plasma level of medication #2 (Mcg/Ml)
42-47	_ _ - _ _ - _ _	Date of plasma level
48-51	_ _ _ _	Dose of medication #2 (mg/day prescribed)
52-54	_ _ _	Weight (in kilograms, [lbs. X .45]) on above date
55-56	_ _	#3 Medication Code
57-60	_ _ _ . _	Most recent plasma level of medication #3 (Mcg/Ml)
61-66	_ _ - _ _ - _ _	Date of plasma level
67-70	_ _ _ _	Dose of medication #3 (mg/day prescribed)
71-73	_ _ _	Weight (in kilograms, [lbs. X .45]) on above date
74-75	0 2	Card number
76	1	Section number
77-80	3 2 5 2	Study number

APPENDIX 4

Interview Form

Mayo Clinic Rochester, Minnesota 55905 Telephone 507 284-2511

Department of Medical Statistics
and Epidemiology

FEELINGS ABOUT HEALTH AND USE OF HEALTH SERVICES
AMONG ADULTS IN ROCHESTER, MINNESOTA

NOVEMBER 1985

CONFIDENTIAL INTERVIEW FORM

(STORE THIS PAGE SEPARATELY FROM INTERVIEW)

INTERVIEW NUMBER __ __ __

(ALSO WRITE INTERVIEW NUMBER ON PAGES 1, 6, 11, 18)

PARTICIPANT'S NAME:

____

PARTICIPANT'S ADDRESS:

____

____

____

PHONE NUMBER __________________________

TIME INTERVIEW BEGINS ____:____

DATE ____/____/____

Column
1-3 __ __ __ INTERVIEW NUMBER

The following statements describe feelings about health in general. For each statement, please choose the answer that matches your feeling about the statement, and write the number of that answer on the line to the left of the answers. If you prefer, think of the answers as a scale running from 1 (strongly disagree) to 6 (strongly agree).
There are no wrong answers.

a) If I get sick, it is my own behavior which determines how soon I get well again.

4 __

Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
(1)	(2)	(3)	(4)	(5)	(6)

b) Having regular contact with my physician is the best way for me to avoid illness.

5 __

Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
(1)	(2)	(3)	(4)	(5)	(6)

c) Whenever I don't feel well, I should consult a medically trained professional.

6 __

Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
(1)	(2)	(3)	(4)	(5)	(6)

d) I am in control of my health.

7 __

Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
(1)	(2)	(3)	(4)	(5)	(6)

e) My family has a lot to do with my becoming sick or staying healthy.

8 __

Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
(1)	(2)	(3)	(4)	(5)	(6)

f) When I get sick I am to blame.

9 __

Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
(1)	(2)	(3)	(4)	(5)	(6)

g) Health professionals control my health.

10 __

Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
(1)	(2)	(3)	(4)	(5)	(6)

Column

h) The main thing which affects my health is what I myself do.

11	_	Strongly Disagree (1)	Moderately Disagree (2)	Slightly Disagree (3)	Slightly Agree (4)	Moderately Agree (5)	Strongly Agree (6)

i) If I take care of myself, I can avoid illness.

12	_	Strongly Disagree (1)	Moderately Disagree (2)	Slightly Disagree (3)	Slightly Agree (4)	Moderately Agree (5)	Strongly Agree (6)

j) When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.

13	_	Strongly Disagree (1)	Moderately Disagree (2)	Slightly Disagree (3)	Slightly Agree (4)	Moderately Agree (5)	Strongly Agree (6)

k) If I take the right actions, I can stay healthy.

14	_	Strongly Disagree (1)	Moderately Disagree (2)	Slightly Disagree (3)	Slightly Agree (4)	Moderately Agree (5)	Strongly Agree (6)

l) Regarding my health, I can only do what my doctor tells me to do.

15	_	Strongly Disagree (1)	Moderately Disagree (2)	Slightly Disagree (3)	Slightly Agree (4)	Moderately Agree (5)	Strongly Agree (6)

Column

-> NOTE TIME INTERVIEWER BEGINS___:___

First I would like to ask you some questions about yourself:

1. What is your birthdate?

16-21 __ __-__ __-__ __ [If earlier than November 1926, or later than November 1967, terminate interview.]

2. What is your marital status? (PROBE: Are you now: married, widowed, divorced, separated, or have you never been married?)

Now married (include common-law marriages)...1 No Answer...8
Widowed ....2 Don't Know..9
22 __ Divorced 3
Separated 4
Never married (include annulments)...........5

Now I would like to ask you some questions about your health in general:

3. Over the past year, how would you compare your health with that of other people your own age? Would you say your own health was:

(READ CHOICES:) Excellent...4 No Answer...8
Good........3 Don't Know..9
23 __ Fair........2
Poor........1

4. How much do you worry about your health in general?

(READ CHOICES:) Not at all......1 No Answer.......8
24 __ Not too much....2 Don't Know......9
Fairly much.....3
Very much.......4

5. Do you do any of the following things?
(READ AND CHECK ANSWERS AND CODE TOTAL SUM OF CHECKS [0-4])

___Exercise less than 3 times a week?
___Smoke cigarettes, cigars, or a pipe?
25 __ ___Drink alcoholic beverages more than 3 times a week?
___Sleep less than 7 or more than 9 hours a day?
No Answer.......8
Don't Know......9

6. Where do you usually get help for your general medical problems?
Mayo Clinic..........................01
Olmsted Medical Group................02
26-27 __ __ Other Doctor in Rochester area........03
Non-Rochester Doctor..................04
Pharmacist............................05
Family................................06
28-29 __ __ Friends...............................07
Chiropractor..........................08
No Answer.............................88
Don't Know............................99
Other (Write below)

Column

7. Sometimes people keep medicines that are leftovers from earlier prescriptions. Do you have any leftover medicines in your house right now?

30 _ No=0 Yes=1 No Answer=8 Don't Know=9

8. Do you have any chronic conditions that require continuous treatment?

No..................................00
31-32 _ _ Yes (ASK: What are they? WRITE BELOW).
No Answer...........................88
33-34 _ _ Don't Know..........................99

35-36 _ _ What are they called?

9. I would like to ask you some questions about a condition you have or used to have, namely seizures. What word do you use to describe the seizures you have or used to have?

________________________ (FILL IN WORD AND SUBSTITUTE FOR "SEIZURES" IN THE REST OF THE INTERVIEW)

10. What is the medical diagnosis for the type or types of "seizures" that you have or most recently had? (WRITE ANSWER BELOW)

10A. (FOR EACH TYPE, ASK: In the last year, how often did you have a "seizure" of this type?)

37-38 _ _ Diagnosis:____

ASK Frequency: None.................................0
1 to 3 per year.......................1
4 to 8 per yr (about every other mo.)..2
9 to 15 per yr (about every month).....3
39 _ 16 to 36 per yr (2 to 3 per month).....4
37 to 52 per yr (about one per week)...5
53 to 200 per yr (several per week)....6
200 plus per yr (about every day)......7
No answer......8 Don't know.....9

40-41 _ _ Diagnosis:____

ASK Frequency: None.................................0
1 to 3 per year.......................1
4 to 8 per yr (about every other mo.)..2
9 to 15 per yr (about every month).....3
42 _ 16 to 36 per yr (2 to 3 per month).....4
37 to 52 per yr (about one per week)...5
53 to 200 per yr (several per week)....6
200 plus per yr (about every day)......7
No answer......8 Don't know.....9

Column

43-44 __ __ 11. In what year did they begin? 19__ __ N.A.=88, D.K.=99

45-46 __ __ 12. In what year were they first diagnosed by a doctor? 19__ __

13. What is the month and year you last had any kind of "seizure"?
88-88=NA 99-99=DK
47-50 __ __-__ __ (MM-YY)

14. Have your "seizures" ever stopped for more than 5 years at a time? IF NO, SKIP TO 15, IF YES, ASK 14A AND 14B:

14A. What year did that most recent period without "seizures" start?

51-52 __ __ Started in 19__ __ 88=NA 99=DK

14B. How many years did it last?

53-54 __ __ Lasted __ __ years 88=NA 99=DK

15. And about how many "seizures" have you had in your whole life? (PROMPT: Read categories)

55 __

1 to 2..............1
3 to 7..............2
8 to 20.............3
21 to 100...........4
101 to 300..........5
301 to 400.....6
More than 400..7
No answer......8
Don't know.....9

16. In the past year, have you taken any prescribed medication for your "seizures"?

56 __

No (GO TO #16A, THEN #19)....0
Yes ASK: "How many types of medication?", CODE NUMBER OF TYPES, MORE THAN 6 TYPES= 7
No Answer....................8
Don't Know...................9

16A. What is the month and year you last took any prescribed medication for your seizures?
57-60 __ __-__ __ (MM-YY)
88-88=NA 99-99=DK

74-75 0 1 Card Number

76 1 Section Number

77-80 3 2 8 0 Study Number

Column
1-3 ___ ___ ___ INTERVIEW NUMBER

17. What are the names of the medications you took in the past year for your "seizures"? ASK FOR EACH:

17A. And what is the prescribed dosage of that medication now? (MG/DAY)

		None..(Skip to # 19).........00	Clonazepam.....(Clonapin)......16
4-5	___ ___	Phenytoin......(Dilantin)....02	Corticotropin..(ACTE)..........17
		Phenobarbital..(Luminal).....03	Diazepam.......(Valium)........18
6-9	___ ___ ___ ___	Ethosuximide...(Zarontin)....04	Ethotoin.......(Peganone)......19
		Trimethadione..(Tridione)....05	Mephenytoin....(Mesantoin).....20
		Carbamazepine..(Tegretol)....06	Mephobarbital..(Mebaral).......21
10-11	___ ___	Primidone......(Mysoline)....07	Metharbital....(Gemonil).......22
		Valproic Acid or	Methsuximide...(Celontin)......23
12-15	___ ___ ___ ___	Sodium Valproate.(Depakene)..10	Methylphenidate..(Ritalin).....24
		Acetazolamide...(Diamox).....11	Phenacemide....(Phenurone).....25
		Amphetamines.(Benzedrine etc)12	Phensuximide...(Milontin)......26
16-17	___ ___	Bromides........(Neurosine)..13	Paramethadione (Paradione).....27
		Chlordiazepoxide (Librium)...14	Mebroin.(Phenytoin & Mebaral)..29
18-21	___ ___ ___ ___	Chlorazepate dipotassium	Phelatin.(Phenytoin & Phenob.).30
		(Tranxene)...15	OTHER..........................28
			(WRITE NAME:)

18. How likely do you think it would be that you would have a "seizure" even while you were taking your medication as your doctor told you? Would you say it was:

22 ___ (READ ANSWERS)

Not at all likely.1	Not applicable....7
Not too likely.....2	No Answer.........8
Fairly likely......3	Don't know........9
Very likely........4	

19. For how many years have you taken (did you take) medications for your "seizures"?

23-24 ___ ___ CODE NUMBER OF YEARS, OR IF NUMBER UNAVAILABLE USE THESE CODES:

None.......00	41-50 yrs...85
1-10 yrs...65	51-60 yrs...90
11-20 yrs..70	
21-30 yrs..75	No Answer...88
31-40 yrs..80	Don't Know..99

20. Have you ever had (did you ever have) a "seizure" while taking your recommended dose of medication?

25 ___

No.....0	Not Applic...7	Don't Know...9
Yes....1	No Answer....8	

Column

21. Do you know of activities, places, feelings, or times that trigger more of your "seizures"? (PROBE: Anything else?)
WRITE ANSWER BELOW, THEN CODE

26-27 __ __
28-29 __ __
30-31 __ __

No, nothing.............00
Decreasing or stopping medications..........01
Sleep deprivation.......02
Alcohol consumption.....03
Prolonged stress........04
Acute stress............05
Menstrual period........06
Diet-related............07

Physical trauma.........09
Drugs including caffeine and alcohol..........10
Flashing lights.........11
Noises..................12
Odors...................13
Other (write below)
No Answer...............88
Don't Know..............99

22. Aside from what you just told me about what triggers your "seizures", why did you first start having "seizures" in the first place? (PROBE: Anything else?)
WRITE ANSWER BELOW, THEN CODE

32-33 __ __
34-35 __ __
36-37 __ __

Single psychological trauma..............01
Prolonged stress......02
Physical trauma.......03
Drug consumption......04
Physiological or anatomical factors..05

Genetic factors.......06
Spiritual factors.....07
"Idiopathic"..........08
Environmental insults.09
No Answer.............88
Don't Know............99
Other (Write Below)

23. What is the single greatest problem you experience now because of your "seizures"?
WRITE ANSWER VERBATIM, THEN CODE

38-39 __ __

No problems............00
Emotional problems.....01
Job-related problems...02
Lifestyle restrictions.03
Driving problems.......04

Marriage and family.05
Not applicable......77
No Answer...........88
Don't Know..........99

Column

24. How would your life be different if you had never had "seizures"?
WRITE ANSWER VERBATIM, THEN CODE

40-41 __ __

42-43 __ __

44-45 __ __

No difference.............00	Improved employment....05
Improved education........01	Driving................06
Improved social life......02	Family and marriage....07
Emotional (more self-confidence, less worry)..03	Not applicable.........77
Less dependence on meds...04	No answer..............88
	Don't know.............99

25. Could you have any of your "seizures" and still think your "seizures" were under control? (IF NO, CODE 0 AND SKIP TO 26.)

25A. How often could you have your seizures while still thinking they were under control?
(PROMPT: READ CATEGORIES)

No, None...............................0
1 to 3 per year........................1
4 to 8 per yr (about every other mo.)..2
9 to 15 per yr (about every month).....3
16 to 36 per yr (2 to 3 per month).....4
37 to 52 per yr (about one per week)...5
53 to 200 per yr (several per week)....6
200 plus per yr (about every day)......7
No answer..............................8
Don't know.............................9

46 __

26. Compared to that number, how well are you doing right now?
READ ANSWERS:

Not at all well....1	No Answer.........8
Not too well.......2	Don't Know........9
Fairly well........3	
Very well..........4	

47 __

27. And how likely is it that you will have "seizures" in the future?
READ ANSWERS:

Not at all likely..1	No Answer..........8
Not too likely.....2	Don't know.........9
Fairly likely......3	
Very likely........4	

48 __

28. How much do your "seizures" currently affect your life? Would you say your "seizures" had:
READ ANSWERS:

No effect..............1	No Answer......8
A mild effect..........2	Don't know.....9
A fairly strong effect..3	
A very strong effect....4	

49 __

Column

29. Have your "seizures" ever caused you to have problems getting or renewing your drivers license?

IF YES, ASK:

29A. Can you tell me a little more about that? What were the problems? WRITE BELOW

50-51 __ __

No.....................00 No Answer......88
Yes..(What?)...........01 Don't know.....99

30. Have your "seizures" ever caused you to have problems obtaining health, life, or car insurance?

52-53 __ __

30A IF YES, ASK FOR EACH: Can you tell me a little more about that? What happened? WRITE BELOW

54-55 __ __

No......................00 No Answer.....88
Yes..(What?)............01 Don't know....99
Health insurance, n.o.s.02

56-57 __ __

Life insurance, n.o.s...03
Car insurance, n.o.s....04

31. Who provides you with most of the medical care for your "seizure" condition?
(DO NOT READ ANSWERS, BUT CODE RESPONSES IN APPROPRIATE CATEGORY)

Family doctor (G.P.)..........01 Not applicable
Neurologist...................02 (no "seizures")..77
Psychiatrist or psychologist..03 No Answer.............88
Social worker.................04 Don't Know............99

58-59 __ __

Other mental health worker....05 Other (write below)
Spouse........................06
Family.(not spouse)...........07
Friends.......................08

60-61 __ __

Minister......................09
Self..........................10

Column

32. How satisfied are you with your present main source of medical care for your "seizure" condition? Would you say you were: (READ ANSWERS:)

62 __

Not at all satisfied..1
Not too satisfied.....2
Fairly satisfied......3
Very satisfied........4
Not applicable (no "seizures")...7
No Answer...........8
Don't know..........9

33. Who do you think gives you the most emotional support for your "seizure" condition?

(DO NOT READ ANSWERS, BUT CODE RESPONSES IN APPROPRIATE CATEGORY)

63-64 __ __

65-66 __ __

Family doctor (G.P.)...............01
Neurologist.........................02
Psychiatrist or psychologist.......03
Social worker.......................04
Other mental health worker.........05
Spouse..............................06
Family..(Not spouse)...............07
Friends.............................08
Minister............................09
Self................................10
Epilepsy support group.............11
Not applicable (no "seizures").....77
No Answer...........................88
Don't Know..........................99
Other (WRITE BELOW)

74-75 0 2 **Card Number**

76 1 **Section Number**

77-80 3 2 8 0 **Study Number**

Column
1-3 ___ ___ ___ INTERVIEW NUMBER

34. How satisfied are you with your present main source of emotional care for your "seizure" condition? Would you say you were: (READ ANSWERS:)

4 ___

Not at all satisfied..1 Not applicable (no "seizures")..7
Not too satisfied.....2 No Answer.......................8
Fairly satisfied......3 Don't know......................9
Very satisfied........4

35. Have you ever been to any of the following people for advice or care for your "seizures"?
(READ EACH CATEGORY, AND IF YES, ASK FOR EACH:)

35A. Did you go to this person (these people) at the same time that you were getting regular care from a medical doctor?

a) Pharmacist (other than to fill a prescription)
5 ___ a 0=No 1=Yes 8=No Answer 9=Don't Know
6 ___ (IF YES: Simultaneous use?) 0=No 1=Yes 8=N.A. 9=D.K.

b) Epilepsy support group
7 ___ b 0=No 1=Yes 8=No Answer 9=Don't Know
8 ___ (IF YES: Simultaneous use?) 0=No 1=Yes 8=N.A. 9=D.K.

c) Bio-feedback therapist
9 ___ c 0=No 1=Yes 8=No Answer 9=Don't Know
10 ___ (IF YES: Simultaneous use?) 0=No 1=Yes 8=N.A. 9=D.K.

d) Nutritionist or nutritional counsellor
11 ___ d 0=No 1=Yes 8=No Answer 9=Don't Know
12 ___ (IF YES: Simultaneous use?) 0=No 1=Yes 8=N.A. 9=D.K.

e) Priest, minister, pastor or other religious representative
13 ___ e 0=No 1=Yes 8=No Answer 9=Don't Know
14 ___ (IF YES: Simultaneous use?) 0=No 1=Yes 8=N.A. 9=D.K.

f) Chiropractor
15 ___ f 0=No 1=Yes 8=No Answer 9=Don't Know
16 ___ (IF YES: Simultaneous use?) 0=No 1=Yes 8=N.A. 9=D.K.

g) Acupuncturist
17 ___ g 0=No 1=Yes 8=No Answer 9=Don't Know
18 ___ (IF YES: Simultaneous use?) 0=No 1=Yes 8=N.A. 9=D.K.

h) Health food store
19 ___ h 0=No 1=Yes 8=No Answer 9=Don't Know
20 ___ (IF YES: Simultaneous use?) 0=No 1=Yes 8=N.A. 9=D.K.

Column

36. Have you ever tried any of the following things on your own to help your "seizures"?

a) Diet (Type or amount of food)

21 __ 0=No 1=Yes 8=No Answer 9=Don't Know

b) Vitamins

22 __ 0=No 1=Yes 8=No Answer 9=Don't Know

c) Stress reduction

23 __ 0=No 1=Yes 8=No Answer 9=Don't Know

37. How much do you worry these days about paying for medical care for your "seizures"? Would you say you worry:
(READ ANSWERS)

24 __

Not at all........1 No Answer..8
Not too much......2 Don't know.9
Fairly much.......3
Very much.........4

38. How do you usually pay for your medical expenses?

25 __

Private Insurance (Blue Cross, etc.).1 No Answer...8
Health Maintenance Organization......2 Don't Know..9
Medicaid.............................3
Medicare.............................4
Self/Family pays.....................5
Workmen's Compensation...............6
Clinic Employee......................7

39. How satisfied are you with the way you now pay for your medical care? Would you say you were:

(READ ANSWERS:)

26 __

Not at all satisfied..1
Not too satisfied.....2 No Answer.........8
Fairly satisfied......3 Don't know........9
Very satisfied........4

40. If you could have any kind of health insurance plan, what would you prefer?

27-28 __ __

Private Insurance (Blue Cross, etc.).01 No Answer...88
Health Maintenance Organization......02 Don't Know..99
Medicaid.............................03
Medicare.............................04
Self/Family pays.....................05
Workmen's Compensation...............06
Other (write in:)
____

Column

41. Have you had any medical appointments scheduled for your "seizures" in the past year? IF NO, CODE #41A as 7 and #42 AS 77.

41A. Sometimes people miss medical appointments. How many medical appointments have you missed that you had scheduled for your "seizures" during the past year?

29 ___

No appointments missed (Code next question= 77) 0
One appointment....................................1
Two appointments...................................2
More than two appointments.........................3
Not applicable- (had no appointments in past year)..7
IF ANSWER IS (7), CODE NEXT QUESTION= 77
No Answer..8
Don't Know...9

42. Why did you miss the appointments you were unable to attend in the past year? (DO NOT READ ANSWERS, BUT CODE APPROPRIATE CATEGORY)

30-31 ___ ___

Couldn't get time off from work 01
Had transportation problems 02
Illness...............................03
Not applicable- (had no appointments or missed none in past year)........77
No Answer.............................88
Don't Know............................99
Other (WRITE BELOW)

43. Some people say that even though in the long run they take "seizure" medication pretty much as directed, they may change their dose for a while. Have you done this, that is, have you ever intentionally or accidently taken more pills or fewer pills than your physician directed?
(IF NEVER DONE—CODE #43 THROUGH #46 AS "7" AND ASK #47)

IF YES, ASK: 43A Have you done this for more than two weeks at a time?
ALSO ASK: 43B Once or more than once?

32 ___

Never done it..(SKIP TO # 47)....0
Yes- 1 time <2 weeks duration....1
Yes- 1 time >2 weeks duration....2
Yes- >1 time <2 weeks duration...3
Yes- >1 time >2 weeks duration...4
Not applicable...................7
No Answer...8
Don't know..9

ALSO ASK:
44. When you did this did you usually take MORE pills than you were directed or did you usually take FEWER pills?

(PROMPT: READ THE FIRST TWO FOLLOWING RESPONSES:)

33 ___

Usually More...............1
Usually Fewer..............2
Not Applicable.....7
No Answer..........8
Don't know.........9

Column

(IF YES, ASK:)

45. How well were your "seizures" controlled the most recent (the last) time you did that?

34 ___

Not at all well controlled..1
Not too well controlled.....2
Fairly well controlled......3
Very well controlled........4
Not applicable...7
No Answer........8
Don't know.......9

(IF YES, ASK:)

46. And why did you do that? (WRITE ANSWER BELOW, THEN CODE)

35-36 ___ ___

37-38 ___ ___

Wanted more protection..............00
Forgot..............................01
Felt side effects...................02
Wanted to have "seizures"...........03
Felt doing well.....................04
Wanted to see what would happen.....05
Other
Not Applicable......................77
No Answer...........................88
Don't know..........................99

ASK IF STILL TAKING MEDICATION, ELSE CODE AS 7

47. Now let's just think about the past week or so. For whatever reason, how much of your recommended "seizure" medication do you think you forgot, missed, decided not to take, or decided to increase?

PROMPT: Where would you place yourself on this scale?

(READ CATEGORIES)

39 ___

none	less than half	half	more than half	same as recc.	more than recc.	not applic.	NA	DK
0	1	2	3	4	5	7	8	9

48. Do you (did you) have any reminders that you use(d) to help you take your medications? What?

(DO NOT READ ANSWERS, BUT CODE APPROPRIATE CATEGORY)

40-41 ___ ___

42-43 ___ ___

No..................................00
Yes- reminders from family........01
reminders from friends.......02
use of medication container..03
use of scheduled activities..04
use of timer or watch........05
Not applicable...(never took meds)...77
No Answer...........................88
Don't know..........................99
Other (write below)

Column

49. Have you ever stopped taking your medication completely for three or more days in a row, without your doctors's advice?
(IF YES, ASK Why?)

44-45 __ __ No=00 Yes (WHY?)=01 No answer=88 Don't Know=99

Why?

50. Have you ever considered not seeing your doctor anymore?
(IF YES, ASK: Why?, AND WRITE BELOW)

46-47 __ __ No=00 Yes=01 Not applic.=77 No Answer=88 Don't Know=99

51. Do you feel any side effects from the medications you take (took) for your "seizures"? What are they?

(FOR EACH ONE MENTIONED, ASK:) How concerned are you about this side effect?
(DO NOT READ ANSWERS, BUT CODE APPROPRIATE CATEGORY)

48-49	__ __	Symptom #1	No/None	00
			Feel slowed down	01
50	__	Concern #1	Drowsiness/Sleepiness	02
			Inability to concentrate	03
51-52	__ __	Symptom #2	Memory problems	04
			Feel addicted	05
53	__	Concern #2	Excessive body hair	06
			Gum growth	07
54-55	__ __	Symptom #3	Tooth problems	08
			Skin problems	09
56	__	Concern #3	Vision problems	10
			Balance, gait problems	11
			Other (Write below)	
57-58	__ __	Symptom #4	Not applicable (never took meds.)	77
			No Answer	88
59	__	Concern #4	Don't know	99

Not at all concerned	1	Not Applicable	7
Not too concerned	2	No Answer	8
Fairly concerned	3	Don't know	9
Very concerned	4		

Other:

Concern level:

Column

52. How likely do you think it would be that you would have a "seizure" while you were off medicine?
(READ ANSWERS)

60 ___

Not at all likely....1   No Answer...8
Not too likely.......2   Don't know..9
Fairly likely........3
Very likely..........4

53. Have you ever had a "seizure" while not taking your recommended dose of medication?

61 ___

No=0 Yes=1 Not applicable=7 No answer=8 Don't Know=9

54. Imagine you were taking medications but still having "seizures," and the medications were interfering with your life—what would you do about your medications if you thought you could get along just as well without them?

62 ___

(0=continue to take, 1=ask doctor, 2=stop meds, 3=cut down)

55. And imagine you were taking medications and not having any "seizures", and everything was going well—what would you do about your medications if you thought you could get along just as well without them?

63 ___

(0=continue to take, 1=ask doctor, 2=stop meds, 3=cut down)

56. Some people who have "seizures" are reluctant to let people know they have or have had "seizures". What proportion of your immediate family knows you have had them?

64 ___

None	A Few	Most	All	NA	DK
0	1	2	3	8	9

57. And what proportion of your close friends?

65 ___

None	A Few	Most	All	NA	DK
0	1	2	3	8	9

58. And what proportion of your close co-workers?

66 ___

None	A Few	Most	All	NA	DK
0	1	2	3	8	9

59. How likely would you be to tell people in each of the following categories about your "seizures"?

(READ EACH CATEGORY, AND READ OPTIONS IF NECESSARY)

Column

a) Your interviewer when applying for a new job?

		Not at all Likely	Not too Likely	Fairly Likely	Very Likely	NA	DK
67	__	(1)	(2)	(3)	(4)	(8)	(9)

b) Your boss?

		Not at all Likely	Not too Likely	Fairly Likely	Very Likely	NA	DK
68	__	(1)	(2)	(3)	(4)	(8)	(9)

c) A casual acquaintance?

		Not at all Likely	Not too Likely	Fairly Likely	Very Likely	NA	DK
69	__	(1)	(2)	(3)	(4)	(8)	(9)

60. Thinking about the people you are around most days, how many of them know about your "seizures"?

70 __

READ ANSWERS:
None of them........1
A few of them.......2
Most of them........3
Almost all of them..4
No Answer...8
Don't Know..9

61. Have you ever had a "seizure" that you didn't tell anyone about? (IF YES, ASK Can you tell me a little about why?)

71-72 __ __

No=00 Yes (WHY?)=01 No answer=88 Don't Know=99

Why:

74-75 0 3 **Card Number**
76 1 **Section Number**
77-80 3 2 8 0 **Study Number**

Column
1-3 ___ ___ ___ INTERVIEW NUMBER

62. Now I would like to ask you a few questions about your activities. I would like to know, on the average, how often you have done each of these things during the past 12 months:

a) visited with friends or neighbors?

		Not at all	1 to 5 times	1x a month or every 2 months	once every 2 or 3 weeks	1x a week	More than 1x a week	NA	DK
4	___	(1)	(2)	(3)	(4)	(5)	(6)	8	9

b) visited with relatives?

		Not at all	1 to 5 times	1x a month or every 2 months	once every 2 or 3 weeks	1x a week	More than 1x a week	NA	DK
5	___	(1)	(2)	(3)	(4)	(5)	(6)	8	9

c) attended meetings?

		Not at all	1 to 5 times	1x a month or every 2 months	once every 2 or 3 weeks	1x a week	More than 1x a week	NA	DK
6	___	(1)	(2)	(3)	(4)	(5)	(6)	8	9

d) gone to church?

		Not at all	1 to 5 times	1x a month or every 2 months	once every 2 or 3 weeks	1x a week	More than 1x a week	NA	DK
7	___	(1)	(2)	(3)	(4)	(5)	(6)	8	9

Now I would like to ask you some questions about your education and occupation.

63. Are you now attending or enrolled in school? IF YES: Is that full time or part time?

8 ___

No 0
Yes, full-time student...1
Yes, part-time student...2
No Answer 8
Don't know...............9

64. What is the highest grade or year of regular school you have ever attended?

CIRCLE ANSWER AND ENTER TWO-DIGIT CODE FOR HIGHEST GRADE (YEAR) ATTENDED

9-10 ___ ___

No School	Grade School		High School		College	
00	01		9		13	
	02		10	ASK	14	
No Answer	03	ASK	11	65	15	ASK
88	04	65	12		16	66
	05				17	
Don't Know	06				18	
99	07				19	
	08				20+	

Column

65. Did you receive a high school diploma or pass a high school equivalency test?

11 ___

Yes (ASK 67)...1 No Answer......8
No ....0 Don't Know.....9

66. What degree or degrees did you receive?
RECORD VERBATIM AND CODE HIGHEST DEGREE RECEIVED ON THE BASIS OF RESPONSES TO (65) AND (66).

Less than high school...................1 N.A....8
High school diploma (or equivalency).....2 D.K....9
Associate, two-year, jr. college degree..3
12 ___ Bachelor's degree.......................4
Master's degree.........................5
Doctorate...............................6
Professional (MD, JD, DDS, etc.).........7

Other (Specify)____________________

67. Besides what you've already told me about your regular schooling, did you ever attend any other kind of school, such as a vocational school?

13 ___

No..(ASK 69)...0 No Answer......8
Yes (ASK 68)...1 Don't Know.....9

IF YES, ASK
68. What was (is) your main field of vocational training?

Business, office work ....1 Other field
Nursing, other health fields ....2 Specify......6
Trades and crafts (mechanic, No Answer.........8
14 ___ electrician beautician, etc.)....3 Don't Know........9
Engineering or science technician;
draftsman, computer programming..4
Agriculture or home economics.......5

69. a) Are you presently employed, or are you unemployed, retired, a student, a housewife, or what?
CHECK AS MANY AS APPLY. IF WORKING NOW, ASK
Is that full time or part time?

Working now 0
Full time ____________________
Part time ____________________
(GO TO OCCUPATION QUESTION — 71)
With a job, but not at work.................1
because of temporary illness, on sick leave, vacation, labor dispute, on strike, bad weather
(GO TO OCCUPATION QUESTION — 71)
15 ___ Unemployed (ASK c)..........................2
Retired (ASK b) 3
In School (ASK b) 4
Keeping House (ASK b) 5
Disabled (ASK b), too ill to work (ASK c)...6
Armed forces (ASK c)........................7
Other (Specify and ASK b) ________________
No Answer................................. 8
Don't Know.................................9

Column

b) Are you looking for work or doing any work for pay now?

No (ASK c)..................................0
Yes, working full time now 1
(GO TO OCCUPATION QUESTION — 71)
Yes, working part time now 2
(GO TO OCCUPATION QUESTION — 71)
16 ___ Yes, looking for work (ASK c)...............3
No Answer...................................8
Don't Know..................................9

c) When did you last work for pay at a regular job or business, either full or part time?

CODE DATE OF LAST WORK (ONE DIGIT) __ __ - __ __ MO YR

Within past 12 months..1 Never worked (SKIP TO 73)..7
1 up to 2 years ago....2
2 up to 3 years ago....3 No Answer...................8
17 ___ 3 up to 4 years ago....4 Don't Know..................9
4 up to 5 years ago....5
5 or more years ago....6

[SKIP DURING INTERVIEW]

70\. SUMMARY CODING OF LABOR FORCE PARTICIPATION (USE RESPONSES FROM a AND b ABOVE TO DETERMINE SINGLE CODING CATEGORY. IF MORE THAN ONE RESPONSE TO a, CODE SMALLEST NUMBER THAT APPLIES.)

IN LABOR FORCE:
Working now (a0, b1, or b2).......1
With a job, but not at work (a1)...2
Unemployed (a2 or b3) 3
18 ___
NOT IN LABOR FORCE:
Retired (a3 and b0).................4
In school (a4 and b0)..............5
Keeping house (a5 and b0)..........6
Unable to work (a6 and b0).........7
Armed service (a7)..................8
Other (a_ and b0)...................9

71\. a) What kind of work do you do (did you do on your last regular job)? What is (was) your main occupation called?

Present Occupation:

19-21 ___ ___ ___

b) Tell me a little more about what you actually do (did) in that job. What are (were) some of your main duties?

Duties:

Column

c) What kind of business or industry is (was) that in? What do (did) they do or make at the place where you work (worked)?

22-23 __ __

Agriculture	1	No Answer...88
Forestry and fisheries	2	Don't Know..99
Mining	3	
Construction	4	
Manufacturing	5	
Transportation, Communications, and Other Public Utilities	6	
Wholesale Trade	7	
Retail Trade	8	
Finance, Insurance, and Real Estate	9	
Business and Repair Services	10	
Personal Services	11	
Entertainment and Recreation Services	12	
Professional and Related Services	13	
Public Administration	14	

72\. a) What kind of work have you done longer than any other? What is (was) your usual occupation called?

24-26 __ __ __ Usual Occupation:

b) Tell me a little more about what you actually do (did) in that job. What are (were) some of your main duties?

Duties:

27-28 __ __ c) What kind of business or industry is (was) that in? What do (did) they do or make at the place where you work (worked)? (USE CODES FROM #71c)

HAND RESPONDENT 1984 INCOME CARD

29-30 __ __ 73. Would you please tell me the number on the card which best represents your total household income in 1984 before taxes? This should include wages and salaries, net income from business or farm, pensions, dividends, interest, rent, and any other money income received by all those people in the household.

IF UNCERTAIN: What would be your best guess?

AFTER INITIAL RESPONSE:
Does that include everyone in your household who has income?
Is that before taxes or any deductions?

31-32 __ __ 74. How many people live in this household? (HOUSEHOLD= PEOPLE WHO TAKE MEALS TOGETHER)

33-34 __ __ 75. And how many people in or out of the household live off that total income?

Thank you very much for your help. That ends the interview. If we have any more questions, or need to check on the information we have already collected, may we contact you again?

YES NO

TIME INTERVIEW ENDS___:___

Column			
		INTERVIEWER CODES:	
35	_	Interviewer:	JAT.......1 Other.....2
36	_	Place of interview:	Home......1 Clinic....2 Telephone.3
37	_	Respondent was:	White...................1 " w. Spanish surname.2 Black...................3 " w. Spanish surname.4 E. Asian................5 Other Oriental..........6
38	_	Interest of respondent:	Uninterested............1 Somewhat interested.....2 Very interested.........3
39	_	Anyone else present?	No......................0 Yes, part time spouse...1 Yes, part time other....2 Yes, most time spouse...3 Yes, most time other....4
40	_	How cooperative do you feel the respondent was?	Not very cooperative....1 Somewhat cooperative....2 Very cooperative........3
41-47	_-_ _ _-_ _ _	Clinic Number	
74-75	0 4	Card Number	
76	1	Section Number	
77-80	3 2 8 0	Study Number	

END