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## An Investigation into the Domain of Experience and Attitudes Concerning Epilepsy

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**AN INVESTIGATION INTO THE DOMAIN  
OF EXPERIENCE AND ATTITUDES  
CONCERNING EPILEPSY**

by

**Claudia B. Lampman**

**A Dissertation Submitted to the Faculty of the Graduate School  
of Loyola University of Chicago in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Philosophy**

**March**

**1990**



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## VITA

The author, Claudia Beth Lampman, is the daughter of the late H. Howard Lampman and Lucille Joan Lampman. She was born May 3, 1962 in New York, New York.

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In August, 1986, Ms. Lampman was granted an assistantship in psychology at Loyola University of Chicago, enabling her to complete the Master of Arts in 1987. Ms. Lampman was awarded a Teaching Fellowship in Psychology in 1988 and a Dissertation Fellowship in 1989 from Loyola University of Chicago. Her dissertation research was also supported by a Behavioral Sciences Fellowship from the Epilepsy Foundation of America.

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## INTRODUCTION

### Statement of the Problem

The National Health Education Committee estimates that approximately one to four percent of the population have some form of epilepsy (see Wright, 1975). Encouraging statistics indicate, however, that today many people with epilepsy achieve a good degree of control over their seizures with anticonvulsant medication (see Karan, 1972). Yet despite the medical advances in epilepsy treatment and control in recent decades, an abundance of research suggests that epilepsy remains a misunderstood and stigmatizing disorder. In fact, a recent government commission concluded that the social problems surrounding the diagnosis or label of epilepsy may often be more serious than the medical condition itself (Commission for the Control of Epilepsy and Its Consequences, 1978). Such "social problems" as negative attitudes, discrimination, misattributions and poor understanding of epilepsy may be rooted in the often dramatic nature of epileptic seizures.

The major symptom of epilepsy is sudden, recurrent seizures caused by an imbalance of electrical activity in the brain. Technically, a seizure is any change in behavior or motor activity that is stimulated by an overload of electrical nerve

cell discharge. The word seizure, therefore, refers to a wide range of phenomena. In most cases, epileptic seizures involve some impairment of consciousness or awareness. However, seizures do not always involve muscular convulsions or movement. For some people with epilepsy, seizures are characterized by only a momentary loss of consciousness (i.e., petit mal). For others, seizures are referred to as grand mal, involving full convulsions and loss of control over the body.

Although the term epilepsy is used broadly to refer to a number of different syndromes, the terms "epilepsy" and "seizure" often denote only one thing: a complete and sudden loss of consciousness accompanied by uncontrollable convulsions or twitching of the limbs (Harrison and West, 1977). Witnessing such a grand mal seizure (or just hearing a description of a seizure) may have a profound effect on observers. According to Murray (1977), "Unlike most situations in which someone becomes suddenly ill, the seizure tends to evoke fear, revulsion and puzzlement rather than sympathy or empathy" (p. 116). The somewhat violent, unpredictable and frightening nature of a grand mal seizure may be related to such documented misattributions as: people with epilepsy are unreliable (Murray, 1977), are likely to be violent (Vinson, 1975), lack self control or are promiscuous (Naylor, 1981), and are temperamental or moody (Vinson, 1975).

The causes of epilepsy may also contribute to some associated stigma. A number of surveys have indicated that many people can correctly locate the cause

of epilepsy to be in the brain (see for example, Caveness and Gallup, 1980). However, a disorder of the brain may be associated with diminished intelligence, retardation, or mental illness. In addition, the sudden "seizure" of a person's thoughts and control over his or her body may be linked to feelings that people with epilepsy are dangerous to themselves and others.

The above discussion suggests that both the historical formation and current perpetuation of negative public opinion about epilepsy may, in part, be related to the nature of the disorder. The following literature review demonstrates that negative attitudes continue to exist among the general public, although there is some evidence to suggest that the situation is improving. The available research on attitudes towards people with epilepsy, however, is limited almost entirely to studies documenting the existence of stigma or discrimination. This field of study is ready for research that will begin to examine factors contributing to the formation of negative stereotypes.

### Purpose of the Present Study

The present study examines how different dimensions and levels of experience with epilepsy are related to attitudes about the disorder. The term "experience" is used to refer to both direct personal encounters with people who have epilepsy and indirect exposures to epilepsy via the media, education, discussion, etc.. The importance of experience in the formation of attitudes is discussed in many social psychological theories of attitude formation and change.

Some theorists discuss the effect of repeated exposure to an object, person or idea on attitude formation (see Zajonc, 1968). There is also research demonstrating that the source of one's beliefs (e.g., from direct experience vs. second-hand information) influences attitude-behavior consistency (see Fazio & Zanna, 1981). The formation of erroneous stereotypes may also be related to lack of direct experience with the object and reliance on what the person has read, heard or observed from family and friends. Finally, the concept of a "person schema" in cognitive social psychology suggests that stereotypes about certain groups of people are actually cognitive structures or schemas containing knowledge, beliefs and specific examples concerning the group in question.

Throughout the literature, there appears to be an implicit assumption, yet very little empirical evidence to demonstrate, that having more experience with epilepsy is related to more favorable attitudes. Given the high degree of control experienced by many patients with epilepsy today, concealment of the disorder is probably becoming easier. Therefore, concealment of epilepsy may remove an important source of epilepsy education, namely experience with competent, capable individuals who are recognized as having epilepsy. Alternatively, because the nature of epilepsy is so unique and possibly fear-provoking, the assumption that experience always leads to more favorable attitudes may be questionable. In fact, some research indicates that some types of experience may be related to the formation of negative attitudes towards epilepsy (Harrison and West, 1977). Currently, little research specifically addresses the issue of experience with

epilepsy. Therefore, one goal of the present study was to examine various aspects of experience with epilepsy among the general public. Such aspects include: the number and frequency of experiences, the direct or indirect nature of experience and the emotional impact of experience. A second aim of this research was to determine whether people with varied amounts and types of experiences differ in their attitudes towards people with epilepsy. Understanding the factors that contribute to the formation and maintenance of negative attitudes is paramount in the field of epilepsy research if successful educational programs are to be designed to enlighten and alter the general public's views about this misunderstood disorder.



## **REVIEW OF RELATED LITERATURE**

The following literature review first presents research on attitudes towards people with epilepsy, followed by a discussion of studies concerning experience with epilepsy. A social psychological framework for investigating the relationship between experience and attitudes concerning epilepsy is then described. Finally, this section concludes with an outline of the goals and hypotheses of the present research.

### **Research on Attitudes Towards People with Epilepsy**

Previous research on attitudes towards people with epilepsy primarily has used survey methodology. A number of nationwide surveys have been conducted both in the United States and abroad. A small number of experimental studies also contribute to the literature on attitudes towards people with epilepsy. Finally, there has been some attempt to develop statistically valid instruments for the measure of attitudes towards people with epilepsy. Each of these research areas is discussed, in turn, below.

*National Surveys: USA.* The most systematic research effort on the study of attitudes towards people with epilepsy has been a series of nationwide public opinion polls conducted by The Gallup organization. At approximately five year intervals beginning in 1949, a series of questions concerning knowledge and attitudes towards epilepsy have been included in larger Gallup public opinion polls. The most recent published findings reported by Caveness and Gallup (1980) indicate generally increasing knowledge, awareness and positive attitudes towards epilepsy over the 30 year period since the research was instituted. For example, in the 1949 poll, 92% of those surveyed reported they had "heard or read about epilepsy," whereas in 1979 this figure had increased to 95%. However, although "awareness" of epilepsy has been high since 1949, the 1979 survey indicated that 39% of the respondents could still not identify the cause of epilepsy (compared to 57% in 1949). Several of the survey items suggest dramatic improvements in attitudes toward epilepsy over the past three decades. Twenty-four percent of those surveyed in 1949 said they would object to having their children associate (in school or at play) with someone who sometimes had seizures or fits. In 1979, only 6% of the survey respondents objected to their children having friends or schoolmates with epilepsy. Similarly, 13% of those surveyed in 1949 felt epilepsy was a form of insanity, whereas only 3% agreed with this in 1979. Finally, over one third of the respondents in the first Gallup survey felt epileptics should not be "employed in jobs like other people," yet only 9% stated this opinion 30 years later. The most favorable opinions toward

epilepsy were found consistently among younger, urban respondents with higher levels of education and employment status. In addition to the attitude questions discussed above, the 1979 survey added an item concerning whether respondents would object to having a son or daughter marry a person who has seizures. The results from this item (18% responding yes) are less positive than the responses to some of the other questions and may reflect a fear that epilepsy would be inherited by later generations.

The Gallup organization has recently conducted another survey on epilepsy (1987), although the results are unpublished to date. The findings from this survey are in some ways surprising, as they do not always follow the patterns of increasing positive trends identified in the previous Gallup studies. For example, almost half (49%) of the respondents in the 1987 sample were unable to identify a cause of epilepsy, compared to 39% in 1979. Furthermore, 16% of the respondents in the 1987 survey thought that epilepsy is "a form of mental illness." These differences in findings may be attributable in part, to various methodological characteristics of the studies. The Gallup polls from 1949 to 1979 conducted face to face interviews, whereas the most recent study used telephone interviewing. The inconsistencies in the results may reflect a tendency to 1) give more socially desirable answers in personal interviews, or 2) give responses consistent with an interviewer bias. Furthermore, the two methods may capture somewhat different segments of the population. An additional source of inconsistency may be changes in wording from the 1979 to 1987 surveys. All of

the earlier Gallup surveys asked if "epilepsy is a form of insanity, or not," whereas the more recent survey used the less inflammatory term "mental illness."

Not only does the more recent Gallup poll indicate that the positive trends identified in earlier surveys may be somewhat tenuous, it also made improvements in methodology over the previous work. The earlier Gallup studies limited the study of knowledge and attitudes towards epilepsy to the questions outlined above, to which respondents could answer either yes or no. The 1987 survey added a number of items and, for some items, improved the response scale. For example, the 1987 survey found that only 3% of respondents believed epilepsy is contagious. However, 41% of the respondents thought that "people often die from epileptic seizures." The more recent survey also had respondents state how strongly they agreed or disagreed (on a 4 point scale) with the following statements: 1) Most epileptics should not drive automobiles, 2) In general, people with epilepsy are dangerous, 3) People with epilepsy should not have children, 4) It is not possible to tell if a person has epilepsy by looking at them, 5) Epilepsy can affect anyone at any age, and 6) Having epilepsy makes other people think less of you and your family. This last question is important because it taps into the general public's perception of whether or not epilepsy is stigmatizing.

Some of the findings from this study are encouraging. Only 7% of those interviewed in 1987 felt that people with epilepsy are dangerous and 12% felt that people with epilepsy should not have children, an improvement over the 1979 survey results. However, one-third felt that having epilepsy makes other people

think less of you and your family and almost one half (44%) felt most epileptics should not drive cars. The finding that one third of those surveyed perceive that epilepsy is viewed negatively by the general public indicates that although many people do not endorse negative opinions about epilepsy they agree that such opinions do exist.

The 1987 Gallup survey did make some methodological improvements over the earlier studies and continued a tradition of contacting large and representative samples of the American public. However, all of the Gallup surveys share a common limitation. Because the epilepsy questions were embedded in larger surveys, both item position and respondent fatigue may be issues of concern. Furthermore, many of the positive findings from the Gallup surveys are not supported by other research discussed below. Finally, these studies have not tapped into the source of erroneous beliefs about epilepsy such as direct or indirect experience.

*National Surveys: Non-USA.* A large study conducted in Sydney, Australia (Vinson, 1975) found that attitudes were prevalent that might "impede the social rehabilitation" of epileptics. A questionnaire was completed by 602 adults in the Sydney metropolitan area in 1972. Although the focus of the survey was on epilepsy, questions were also asked about the deaf, diabetics, and people "crippled since birth" for comparison. Forty-five percent of the sample considered epilepsy to be a mental disorder, a much higher percentage than found by the Gallup

surveys. In response to the question "How would you describe epileptics (or diabetics, etc.) as people, that is their personality or nature," 13.2% of the respondents mentioned that epileptics were temperamental or moody. Diabetics, the deaf and crippled people were each described as moody or temperamental by only about 6% of the sample. Another important finding is that more than half of the sample felt that epileptics were likely to be capable of violent crime. The other three groups were rated by approximately 30% of the sample as likely to be capable of violent crime. Although these figures are also high, the difference between epilepsy and the other three groups was statistically reliable.

Attitude surveys on epilepsy have also recently been conducted in Italy and Finland. Canger and Cornaggia (1985) conducted personal interviews with about 1000 Italian adults using a questionnaire adapted from Caveness and Gallup (1980). Only 73% of the sample was familiar with epilepsy, however, among those aware of epilepsy, 8% felt it was a form of insanity, 15% felt epileptics should not hold jobs like other people, and 11% would object to their children associating with epileptic classmates or friends. These results indicate somewhat more negative attitudes than those found by Caveness and Gallup (1980).

A similar study in Finland (Iivanainen, Uutela and Vilkkumaa, 1980) found that 95% of the respondents (N=2,272) were familiar with the term epilepsy, although 36% were unable to identify a cause. Nineteen percent of the sample said they would object to their child playing with an epileptic child but only 1% indicated an epileptic child should not go to a regular school.

Furthermore, only 1% said they would "quit their jobs immediately if they were asked to work with an epileptic person." Finally, Iivanainen et al. (1980) found that attitudes were positively correlated with age (i.e., attitudes became more favorable with age). This is in contrast to the Gallup survey findings that younger people had more favorable attitudes towards epilepsy. Methodological characteristics may explain some of the inconsistencies with these data. Iivanainen et al. (1980) used mail questionnaires to contact respondents. There are several potential problems with the use of a mail questionnaire in this type of study. First, mail questionnaires are generally not the method of choice for surveys that contain questions on knowledge or sensitive issues. Second, it may be that people who hold negative attitudes or know nothing about epilepsy are less likely to return the survey. Finally, the authors noted that economic conditions and high unemployment may have influenced the survey results producing much less prejudice on economically-related items such as asking if people would quit their jobs immediately than on less extreme attitude questions.

*Other Studies Concerning Attitudes Towards People with Epilepsy.* In 1980, Hansotia, Johnson, Bauman, Sommers and Fuchs administered a series of questionnaires assessing knowledge, attitudes and awareness of epilepsy to samples of clinic employees and members of the general public. The employee sample consisted of 200 volunteers holding nonmedical positions at a Wisconsin clinic. Employees known to have frequent contact with epilepsy patients were

excluded from the study. The general public sample was obtained by distributing questionnaires to randomly selected adult family members accompanying patients to the clinic for conditions that were not epilepsy related (N=200).

Although the results of this study suggested that the clinic employees were more knowledgeable about epilepsy and more accepting of persons with epilepsy, both groups of respondents demonstrated negative attitudes towards epilepsy in general. In fact, the authors concluded, "Indeed, without variation relatively few study respondents indicated appropriate knowledge, understanding or awareness about epilepsy" (p.25). However, the actual questionnaire items, response scales and numerical findings were not reported consistently in this study, making further interpretation of the results impossible.

Breger (1976a and 1976b) conducted a series of studies on adolescents' attitudes towards epileptics of the same age group. A two-part survey on 1) awareness and knowledgeability regarding epilepsy and 2) social acceptance of epilepsy, was administered to 956 adolescents in 1973. Breger hypothesized that a lack of social acceptance, understanding and awareness of epilepsy would exist among the adolescents surveyed. However, the general conclusions of these studies stated that adolescents exhibited "high levels" in all of these areas. Although the results were positive in a number of areas, there was also support for several important negative attitudes towards epilepsy that the author failed to address adequately. For example, results on items concerning the emotional behavior and institutionalization of epileptics indicated that more than one-third



of the respondents stated epileptic individuals are "usually emotionally disturbed and likely to show abnormal and violent behavior." Similarly, almost one third of the students felt that most epileptics should attend special classes or schools. Breger (1976a and 1976b) also found that approximately 25% of the adolescents felt that epileptics were of lower intelligence than most people. Therefore, Breger's conclusion that there is high social acceptance and knowledge about epilepsy among adolescents seems to gloss over some important results.

Grand, Bernier and Strohmer (1982) conducted a study of attitudes towards disabled persons, including amputees, people with cerebral palsy, people with epilepsy and the blind. A sample of 191 faculty and staff members from a northeastern university completed the Disability Social Relationship Scale. This instrument consists of three subscales on Work, Dating, and Marriage and is designed to measure attitudes towards social situations and social intimacy with regards to disabled persons. Respondents were asked to agree with statements like "If I were to date a \_\_\_\_\_, I would be uncomfortable because people would stare," or "If I were to work with a \_\_\_\_\_, I would not be surprised if he or she fell behind in work," or "Marriage to a \_\_\_\_\_ would be difficult because this person would not be able to take full responsibility as a parent."

Grand et al. (1982) found that epilepsy was ranked as highest in social acceptance across the Work, Dating, and Marriage subscales, however, not significantly higher than the amputees. The authors stated they felt these results were unusual given past research finding negative attitudes toward epilepsy, but

that the results might be due to the fact that "... our highly educated sample was more knowledgeable about this disability, resulting in less than typical stigma and misinformation about the functional limitations of epilepsy" (p. 172). However, these results may also have been affected by the choice of comparison groups in this study. Because many of the items in these scales concern day-to-day life with disabled people, the person with a constant physical handicap such as cerebral palsy, blindness or amputation would likely be rated as having more daily problems. Furthermore, the issue of heritability may have influenced results on the Dating and Marriage scales because cerebral palsy and blindness may be perceived as more likely to be inherited than epilepsy or disabilities related to amputation. Finally, people with epilepsy (and possibly amputees with artificial limbs) have less noticeable disabilities, thus they would not arouse as much "staring," etc.. Although the results of this study do appear positive with respect to epilepsy, they are only discussed relative to the other disability groups. It cannot be determined from this report what the average social acceptance scores for epilepsy indicate in a more general context, or what social acceptance may be based on.

A study by Ries (1977) on public acceptance of the disease concept of alcoholism used people with epilepsy and the blind as comparison groups. Interviews with approximately 300 people indicated that the amount of tolerance people showed toward epileptics varied with the role relationship in question. For example, more than half of the respondents said they would not want their

child to marry an epileptic and about one fourth would not rent a room to someone with epilepsy. However, only 11% objected to working with an epileptic and 5% did not want to have an epileptic neighbor. The social distance figures for alcoholics were somewhat more unfavorable than for epileptics and the figures for the blind were more favorable. Again, interpretation of these results is difficult given the lack of information concerning the basis of such opinions.

*Epilepsy as an Independent Variable in Experimental Studies.* Research on attitudes towards people with epilepsy has primarily involved surveys of the general public. However, data from several experimental investigations also provide evidence concerning stereotypic views of epilepsy.

Hansson and Duffield (1976) asked 100 college students to identify people from two sets of "lineups" whom they thought were epileptic. The lineups consisted of photographs of either male or female college students taken from college yearbooks. Independent judges previously rated 100 photographs of each sex on a 1-10 scale of attractiveness. From these photos, 10 male and 10 female were selected for each lineup that were evenly distributed along the attractiveness scale. Only photographs with small standard deviations in attractiveness ratings were chosen. Thus five of the photographs in each lineup were rated as attractive and five were rated as unattractive. Subjects were told that one person in each lineup had been diagnosed as having grand mal epilepsy, and that they should try to choose that person from the lineup.

The hypothesis that subjects would be more likely to attribute epilepsy to unattractive persons was supported. Eighty-three percent of the subjects selected a photograph with an unattractive rating from the male lineup and 69% selected an unattractive photo from the female lineup. Moreover, these results were not affected by either the amount of time allowed to make the decision (one vs. five minutes) or personality variables such as self-esteem, level of empathy, birth order or perceived similarity to the target person as determined by a post-lineup questionnaire. Finally, personal acquaintance with someone with epilepsy did not influence the results.

A field experiment by Hopkins-Best (1987) investigated the hypothesis that stereotypes about the limited career potential of women, people with epilepsy and the hearing impaired would affect high school guidance counselors' agreement with students' choices of careers. Six versions of a case study about a fictitious student "Chris Brown" were randomly distributed to guidance counselors in the Wisconsin high school system. Chris was described as an "average" student in all of the versions. The experimental manipulation involved describing Chris as 1) male or female (with no mention of disability), 2) hearing impaired and male or hearing impaired and female, or 3) having controlled epilepsy and male or female.

The results of this study indicated some stereotyped thinking among counselors with respect to sex and disability. Counselors were significantly more likely to feel professional careers were appropriate for the case studies specifying

that Chris Brown was male and non-disabled. Unfortunately, the authors did not report analyses separately for the two disability conditions (epilepsy and hearing impairment). However, the results of this study and those of Hansson and Duffield (1976) are compelling in that they demonstrate a tendency even among well-educated people to hold stereotypic views of people with epilepsy.

*Measurement of Attitudes Towards People with Epilepsy.* Antonak and Rankin (1982) have made another recent contribution to the study of attitudes concerning epilepsy with their work on the development of the ATPE or Attitudes Towards Persons with Epilepsy Scale. This instrument was designed to be a brief, reliable and valid measure of knowledge and attitudes about persons with epilepsy. The ATPE consists of 32 statements that respondents rate on a 6-point scale, ranging from -3 (I disagree very much) to +3 (I agree very much). Antonak and Rankin (1982) present data from item analyses that demonstrate the scale's reliability and homogeneity. Factor analysis revealed three factors which Antonak and Rankin labeled Prejudicial Stereotypes, Behavioral Misconceptions, and Behavioral Optimism. Furthermore, they cite preliminary support for the scale's construct validity from studies relating various demographic and respondent characteristics to scale scores. The ATPE was administered to approximately 250 people enrolled in various degree programs at the University of New Hampshire. Multiple regression analyses using age, sex, education level and professional specialization as independent variables, and attitudes toward

epilepsy as the dependent variable found that level of education was the best predictor of attitudes. In addition, "special service providers" (e.g., special educators) had significantly more accepting attitudes than people from other majors. However, they also found that females had significantly more accepting attitudes than males.

Antonak and Rankin (1982) suggested the ATPE will be useful in studies concerning the correlates, structure, modification and formation of attitudes and knowledge about epilepsy. To date, however, the only other published work utilizing the ATPE is a study conducted in West Germany by Rader, Ritter and Schwibbe (1986) that administered the ATPE to a sample of volunteer respondents similar to the original sample used by Antonak and Rankin (1982). Both Antonak and Rankin (1982) and Rader et al. (1986) limited their studies with the ATPE to well educated samples. Clearly this limits the external validity of these findings but also questions whether this scale will provide different results when administered to more heterogeneous samples.

### Research on Experience with Epilepsy

Several of the attitude surveys reviewed above also included questions concerning experience with epilepsy. However, the assessment of experience in these surveys was limited to the following two questions:

- 1) Have you ever known anyone with epilepsy?
- 2) Have you ever seen a seizure?

With the exception of Breger (1976a), the findings from the studies that addressed these two issues suggest that approximately half of the population have seen a seizure at some point in their lives and that slightly more than half have personally known someone with epilepsy (Canger & Cornaggia, 1985; Caveness and Gallup, 1980; Caveness, Meritt & Gallup, 1974; Iivanainen et al., 1980). Breger (1976a) addressed the issue of experience by following up affirmative responses to the question "Are you familiar with the condition called epilepsy" with the question "How did you first learn about it?" Given that the study addressed adolescent attitudes, it is not unusual that a much smaller percentage (28%) reported knowing someone with epilepsy. Surprisingly, however, only 1% of the 956 adolescents reported having personally seen a seizure. This does not necessarily indicate that only 1% of the sample had seen a seizure -- they may have reported they learned about epilepsy in another way.

An additional line of research addresses epilepsy disclosure. Sociologists Schneider and Conrad (1983) interviewed eighty people with epilepsy from 1976 to 1979. They found that people with epilepsy tend to use "strategies of selective concealment" concerning their seizure disorders. One woman described her situation this way:

"Well, I understand it now and I'm not afraid of it. But most people are unless they've experienced it, and so you just don't talk to other people about it, and if you do, never use the word 'epilepsy.' The word itself, I mean job-ways, insurance-ways ... anything, the hang-ups there are on it. There's just too much prejudice so the less said about it the better" (p.153).

Although this comment highlights the importance of experience in dispelling myths about epilepsy, some of Schneider and Conrad's respondents discussed how seizures can be frightening to observers:

"I can't use the word 'horrible,' but they think ... it's ugly. It is. It's strange. It's something you're not used to seeing" (pp. 153-154).

"It's one of those fear images; it's something that people don't know about and it has strong negative connotations in people's minds. It's a bad image, something scary, sort of like a beggar; it's dirty, the person falling down and frothing at the mouth and jerking and the bystanders not knowing what to do. It's something that happens in public that isn't nice" (p.154).

Research by Harrison and West (1977) further demonstrates that experience with epilepsy is not always positive. Interviews with 114 people in Bristol and Oxford, England, suggest that the public view of epilepsy is primarily the image of a grand mal seizure. Eighty-two percent of those interviewed mentioned at least one of the following seizure characteristics: 1) falling and/or collapsing, 2) loss of consciousness or awareness, 3) twitching/jerking of limbs, 4) foaming at the mouth, and 5) biting one's tongue. Characteristics of less obvious forms of seizures were described by only 8% of the sample.

Harrison and West (1977) also examined differences between respondents who had experience with epilepsy and those who did not. They found that roughly half of the respondents had experiences with epilepsy that could be characterized as "entirely negative." Of those respondents who had observed seizures, 20% mentioned that epileptics were violent or aggressive. A similar number described the individual with epilepsy as highly strung, retarded or nervy. Several



important issues are raised by this research. First, direct observation of seizures and relationships with people who have epilepsy are very different types of experience. This research suggests that some types of experience may generate or confirm negative attitudes. The authors concluded: "We cannot condemn the opinions expressed in this survey as willful and malicious prejudice. They are at least in part based on experience, so cannot simply be written off as ignorance" (p. 282). Secondly, encounters with epilepsy that are salient (i.e., observation of a grand mal seizure) are likely to have a more profound impact on individuals than less extreme experiences. Finally, nondisclosure of seizure disorders by many patients with epilepsy may aid in limiting public exposure to all forms of epilepsy, but particularly less salient forms (i.e., petit mal).

Many questions about experience with epilepsy are left unanswered. First, none of the existing studies has addressed the overlap between knowing someone with epilepsy and having witnessed a seizure first hand (i.e., whether those who know people with epilepsy are the same group of people who have seen seizures). Secondly, only one of the studies specifically addressed the relationship between attitudes and experience (Iivanainen et al., 1980). This study found a positive correlation between experience and attitudes (those with some experience were more likely to have positive attitudes). However, this study's limitations (discussed above) make these findings at best preliminary.

Other aspects of experience with epilepsy that should be addressed in further research include:

- The amount of experience
- The relationship between observers and seizure victims
- Where direct encounters occurred (in public or private)
- The age and sex of the seizure victims
- The types of indirect experience the public has
- The emotional impact of viewing seizures on the observer
- The types and symptoms of seizures observed

To review, the current status of research on attitudes towards epilepsy indicates that negative public opinion continues to exist, although there is some evidence to suggest that positive gains have been made in recent years. Data from both surveys and experimental studies confirm that stereotypes about epilepsy persist, even among the well educated. The striking and forceful nature of many epileptic seizures is proposed as contributing to the generation and persistence of such negative opinions. Despite commentary throughout the psychosocial literature on epilepsy that alludes to this relationship, there is a dearth of research that specifically addresses experience with epilepsy or its association with stereotypic beliefs about people with epilepsy. The following section considers potential relationships among attitude and experience variables from a social psychological perspective.

## Social Psychological Framework

Psychologists use the term "schema" to describe a cognitive structure containing knowledge, beliefs and instances of the attributes of a given concept, as well as information about the relationships among these attributes (see Fiske & Taylor, 1984). Schemas serve to organize information in memory, guide perception of new data, and influence the manner in which inferences are made. A "person schema" contains a person's understanding of the psychology of certain groups of individuals, including such things as typical traits or attributes, pieces of knowledge about the group of people and specific examples. Person schemas help us to process information about people efficiently and easily, allow us to place people into categories and evaluate whether behaviors and information are schema-relevant and congruent.

The consideration of beliefs concerning people with epilepsy in terms of a schema framework raises several important issues. The concept of an "epilepsy schema" recognizes that specific instances of people with epilepsy (i.e., experiences) are an integral part of a person's cognitive structure of beliefs. However, not all types of experiences are equally likely to become part of a schema. Research suggests that experiences that are "salient" in some way have a higher probability of being attended to and therefore a greater likelihood of being encoded in memory (see Bargh, 1982). Events that are unexpected, novel or otherwise noticeable have been shown to be processed more deeply and attract more attention (e.g., Fiske, 1980). In general, the more attention paid to an

attitude object or person, the more coherent one's impression of the object becomes (Fiske & Taylor, 1984). Related to salience is the concept of vividness, which is also thought to influence information processing (Nisbett & Ross, 1981). Information or events that are vivid are described as emotionally interesting and temporally or spatially proximate. Given the salient and vivid nature of grand mal seizures, this type of direct experience may have more impact on the formation of an epilepsy schema than less striking or pallid information.

Experiences that have been stored in memory as part of an "epilepsy schema" may also affect how later information is processed. There is evidence to suggest that once a schema is formed, perception is biased toward schema-consistent information (see Fiske & Taylor, 1984). Together with the above discussion of the impact of salient information, this suggests that a single, salient but frightening episode may have a long lasting impact on a person's beliefs about epileptics, even if later examples don't confirm beliefs associated with the experience. For example, the observation of a seizure in childhood might have such a profound impact on the development of a schema about people with epilepsy that meeting someone with epilepsy who does not "fit in" to the schema may be explained away as an exception and then forgotten, or ignored.

In general, research on schema development indicates that the more frequently one comes in contact with schema-relevant instances, the more abstract the schema becomes. Abstractness is considered a property of well-developed schemas because we generalize schemata from examples of the category in

question. Consider the development of a "driving schema." The first car one learns to drive will have a certain feel to the clutch, brakes, shifting patterns, etc. At that point in time, the "driving schema" is said to be concrete, and tied almost exclusively to the single concrete experience with that first car. After driving a number of different cars, the driver begins to form more abstract or general conceptions of clutches, brakes and shift patterns. Similarly, mature schemas are also more likely to be complex. As one begins to drive a number of other automobiles, one may start to notice and evaluate aspects of the cars that did not seem important when first learning to drive. For example, the gas mileage, safety features and comfort may start to become important. These experiences lead to greater complexity of schemata which in turn moderates judgement. As schemas develop and become more complex and abstract, the object or group of persons in question may become less clear-cut, and thus one's judgements may be less extreme. To summarize, with repeated experiences schemas become more complex, more abstract and possibly more moderate. The above discussion of schemas suggests that limited but salient experiences with epilepsy (e.g., seeing a seizure) may lead to schemas that are concrete and immature, yet resistant to change because of the greater information processing and memorial accessibility associated with salient events. Repeated exposures to epilepsy (e.g., knowing someone with epilepsy), however, may lead to schemas that are well-formed, abstract and more flexible.

A related area of research in the attitude formation literature demonstrates that repeated exposure to an object is associated with stronger attitudes towards the object (see Zajonc, 1968). Research has shown that the frequency of exposure to an object is positively related to attitudes about the object (see Zajonc, 1968 for review). However, this attitude enhancement effect only seems to hold with exposure to neutral or positive stimuli and not for negative stimuli. Individuals who know other people with epilepsy are likely to have larger numbers of experiences than people who have never known anyone with epilepsy. Therefore, continual contact with a person who has epilepsy may serve to facilitate or strengthen positive attitudes towards people with epilepsy in general, assuming the initial contact was not negative.

Although a number of theorists in social psychology discuss the importance of experience in attitude formation, Fazio and Zanna's (1981) research specifically addresses differential effects of direct experience and indirect experience on attitudes. Their work suggests that direct experiences may lead to stronger attitudes and play a larger role in attitude-behavior consistency than indirect experiences. This has important implications for epilepsy research in that people with direct experiences may be more likely to act (or not act) in response to a situation concerning an individual with epilepsy. Such situations might include discriminatory behavior, aiding a seizure victim or just associating with people who have epilepsy.

Recent research also suggests that experience weighted by its quality and emotional impact is more related to attitudes than mere amount of experience towards a stigmatized group (Archambault & Edwards, 1989).

In sum, research from both the cognitive social psychology literature and traditional literature on attitude formation suggests that experience may be a critical factor in the development and persistence of negative beliefs about people with epilepsy.

### The Present Study

This study addressed the above issues by interviewing a sample of individuals with regard to their experiences with and beliefs about epilepsy. The specific aims of this research were to: 1) describe in detail the range of experience with epilepsy among a sample of the general public, and 2) examine whether individuals with various levels and dimensions of experience differ in their attitudes about epilepsy. The following hypotheses were tested. First, based on the concept of salience, do individuals with only limited, but direct experience in the form of witnessing seizures have more negative attitudes than individuals with either greater ranges of experiences or only indirect experience? Second, based on the notion that repeated exposure results in more flexible schemas and more favorable attitudes, do respondents reporting they know people with epilepsy have more accepting views than people who do not personally know anyone with a seizure disorder? A third hypothesis tests whether individuals with

direct experience of any kind have stronger attitudes than people with only indirect experience. This hypothesis follows from research demonstrating that direct experience with an object is associated with stronger attitudes about the object than only indirect experience (Fazio & Zanna, 1981). Finally, given that schema development is based on experience, do people with "more" experience with epilepsy have more accepting attitudes? In addition, various demographic characteristics, including age, sex, education level and other personal or family handicaps were examined in conjunction with the experience and attitude variables.



## **METHOD**

### **Overview**

The primary objective of this research was to survey members of the general public about their experiences and attitudes concerning epilepsy. Although most previous research in this area has used personal interviews or self-administered questionnaires, the current study used telephone interviews to gather information. A telephone survey was the method of choice for the following reasons. First, personal interviews involve a great deal of time and expense because of travel costs, extensive training and follow-up contact. Secondly, because epilepsy is not a salient or familiar topic to the average person, a mail survey might yield very low response rates and/or encourage people to complete the survey with the aid of family members or friends. Given that analyses would be conducted that differentiate individuals based on levels of experience, "group" answers (e.g., I've never seen a seizure, have you?) could potentially contaminate the data.

### **Subjects**

Telephone interviews were conducted with a sample of 292 adults (over the age of 18) living in the Chicago metropolitan area. A random sample of

1,500 phone numbers was drawn from a Chicago telephone directory by selecting one number from each page. Each page was divided into six sections, and a number was chosen randomly from one of these sections on each page. These numbers were then altered by subtracting one from the last digit in the sequence. This method provided a random sample of phone numbers with Chicago area prefixes.

Eight trained interviewers (graduate and undergraduate students in psychology) conducted the interviews between June 1st and October 14th, 1989. Half of the interviewers were female. All phone calls were placed between 5:30 PM and 10:00 PM on Monday through Thursday evenings, or between 11:00 AM and 4:30 PM on Saturdays. The 292 completed interviews represent a completion rate of 59% (i.e., a valid respondent at 494 or 59.1% of the households actually contacted consented to an interview). Of the 292 interviews, 21 (7.2%) were eliminated from further analysis due to incomplete data, resulting in a total sample size of 271 subjects.

### Materials

The questionnaire contained a section on attitudes towards people with epilepsy, sections on various types of experience with epilepsy, and a demographic section (see Appendix). In approximately half of the interviews (49.8%) participants were asked to respond to the attitude statements before discussing their experiences. The remaining interviews were conducted in the reverse order. This

allowed examination of any effects on attitudes due to the prior recall of experience with epilepsy (see results). The demographic items were always administered as the last part of the survey.

*Attitudes Towards People With Epilepsy.* The attitude section of the survey contained 27 items based on questions used in previous research on attitudes towards people with epilepsy (see Antonak & Rankin, 1982; Breger, 1976(a); Caveness et al., 1980; Gallup, 1987). All of the items were worded in the form of statements, and respondents were asked to listen to each statement about people with epilepsy (e.g., people with epilepsy are usually less intelligent than most people) and then respond in a two-part format. First, they were asked to indicate whether they agreed or disagreed with the statement. Next, respondents were asked to what extent they agreed or disagreed based on a 3-point scale. A response of 3 indicates strong agreement or disagreement, a response of 2 indicates moderate agreement or disagreement and a response of 1 indicates slight agreement or disagreement. Interviewers recorded agree responses on a scale from +1 to +3 and disagree responses on a scale from -1 to -3. Respondents were not explicitly offered a response choice of "don't know" or "no opinion" however, if they had considerable difficulty or objected to answering a question, the interviewer assigned a score of zero for that item, and it was eliminated from analysis. Because a score of zero did not indicate "hard to

decide, but rather "unable to respond," such scores were eliminated from further analysis.

The 27 items were randomly arranged on the questionnaire, and one third of the statements were worded so that an agree response would indicate a positive attitude. The remaining items were worded so that a disagree response would indicate a favorable answer. After data collection, the negatively worded items were recoded so that a positive sign indicates a more favorable opinion.

*Experience with Epilepsy.* The experience sections of the survey contained both fixed and free-response questions concerning direct and indirect experience with epilepsy. Two series of questions were used to address the issue of direct experience. First, respondents were asked if they had ever known someone with epilepsy. Affirmative responses were followed up with questions concerning the person with epilepsy, including his or her age, sex, relationship to the respondent and duration of acquaintance with the respondent. Respondents were also asked questions about the epileptic person's daily life and capabilities. If a respondent reported knowing more than one person with epilepsy, they were asked to respond to the above questions about the person they knew with epilepsy whom "they felt closest to," or "know the best."

The second series of questions on direct experience with epilepsy concerned witnessing seizures. Respondents who reported they had seen someone have an epileptic seizure (in person), at least once, answered questions

about the "most recent time" they had seen a seizure. These questions included their relationship to the person having the seizure, the place where the seizure occurred, the victim's age and sex, and a description of the event. They were also asked to rate the emotional impact of viewing the seizure on a number of attributes such as frightening, memorable and disturbing.

Respondents were also asked a number of questions concerning indirect types of experience with epilepsy. These questions addressed reading about epilepsy, viewing seizures on television or in movies, and discussions about epilepsy with family or friends.

*Demographics.* Various demographic variables were also measured. These variables include characteristics identified in previous research as related to attitudes towards people with epilepsy, including age, sex, and level of education. In addition, respondents were asked whether they, or any of their family members had any chronic health conditions. Finally, respondents were asked if they had ever worked in a field related to medicine, and if so, what type of job they held.

### Procedures

The study was conducted at Loyola University of Chicago with trained student interviewers. Evening and weekend interview times were established in order to maximize the probability that respondents would be home, obtain a balanced sex distribution, and minimize possible annoyance due to calls inter-

rupting meals, etc.. At the beginning of each call, interviewers identified themselves as members of a Loyola University research team conducting a study on epilepsy. After contact was made with an adult in the household, the respondent was asked if he/she presently had time to complete a brief, confidential interview. If the respondent said no or consented, but was unable to complete the survey at that time, the interviewer asked if he/she could be contacted at a more convenient time the following day. Busy signals or no answers were followed up with as many as 6 call backs (mean number of callbacks = .74). At the end of each interview respondents were thanked, and asked if they had any questions about the study. If a question could not be answered by the interviewer, the respondent was asked for his/her name and address, to be contacted by the study director.

## **RESULTS**

### **Overview**

The first part of the results section is primarily descriptive; respondent demographics are summarized and the major findings for each part of the survey are presented. The remainder of this section presents the results of analyses used to examine hypotheses concerning predicted relationships among experience and attitude variables in the study.

### **Descriptive Data**

*The Sample.* Participants in this study were primarily female (68%), with a mean age of 40.1 years (s.d. = 15.7, range from 18 to 88 years). About 33% of the sample graduated from college, 87.7% completed high school, and 10.1% did not graduate from high school (see Table 1 for education breakdown). About one fourth of the sample stated they had worked in a field related to medicine (see Table 2). Forty-four (16.5%) of the respondents reported they personally had a chronic health condition, and 27.3% of the sample had a close family member with a chronic health condition. (Tables 3 and 4 summarize the health conditions respondents reported for themselves and families, respectively.)

Table 1

**Summary of Respondents' Level of Education**

<b>EDUCATION LEVEL</b>	<b>N</b>	<b>%</b>
Elementary School	5	1.9
Some High School	22	8.2
Graduated High School	71	26.5
Vocational School	6	2.2
Some College or A.A. Degree	75	28.0
Graduated College	49	18.3
Some Graduate Work	7	2.6
Holds Graduate Degree	33	12.3



Table 2

Jobs Held by Respondents in Fields Related to Medicine

TYPE OF JOB	N	%
Medical Technician/Assistant	16	5.9
Nurse	15	5.5
Nurses Aide	11	4.1
Hospital Volunteer	8	3.0
Secretary/Administrative Position	5	1.8
Social Worker	3	1.1
Researcher	3	1.1
Orderly	2	0.7
Pharmacy	2	0.7

Table 3

Summary of Chronic Health Conditions of Respondents

<b>HEALTH CONDITION</b>	<b>N</b>	<b>Percent of Total Sample with Condition</b>
Heart disease or Hypertension	15	5.5
Asthma	12	4.4
Other (not reported)	6	2.2
Blood Disorder	3	1.1
Arthritis	3	1.1
Deaf or Mute or Blind	2	0.7
Diabetes	2	0.7
Epilepsy	1	0.4

Table 4

Summary of Chronic Health Conditions Possessed by Respondents' Family Members

HEALTH CONDITION	N	Percent of Total Sample with Condition
Heart disease or Hypertension	23	8.5
Diabetes	15	5.5
Other (not reported)	12	4.4
Asthma	8	3.0
Epilepsy	5	1.8
Arthritis	4	1.5
Parkinsons Disease	3	1.1
Deaf or Mute or Blind	2	0.7
Blood Disorder	1	0.4
Autism	1	0.4

*Attitudes Towards People with Epilepsy.* An attitude scale was created by averaging over the 27 items in the attitude portion of the questionnaire. The Cronbach's alpha for this scale was .86, indicating the scale is internally consistent.

Prior to conducting any data analysis, a *t*-test was used to examine whether there were any significant differences in attitudes that might be attributable to the order in which the questionnaire was administered. The mean attitude scores of respondents who completed the experience sections of the questionnaire first were compared to those who responded to the attitude items first. The findings of this test suggest that the order of the questionnaire is not reliably related to respondent attitudes ( $t(269) = -0.91, n.s.$ ).

The results of the attitude portion of the survey are summarized in Table 5. The responses to some of the items are quite positive. For example, very few respondents felt that: people with epilepsy are dangerous (2.6%), are less intelligent than most people (4.1%), are not just like anyone else when their seizures are controlled (3.7%), should be denied equal employment opportunities (3.0%), are contagious (2.2%), or should be denied insurance benefits (5.6%).

Unfortunately, one in seven respondents (14.1%) agreed that epilepsy is a form of mental illness, 16.7% of the respondents stated that people with epilepsy are accident-prone, 13% agreed that epileptics are often emotionally disturbed, and 15.7% said people with epilepsy are likely to show abnormal or violent behavior.

Table 5

Summary of Responses to the Attitudes Section of the Questionnaire

ITEM	mean (s.d.)	% -3	% -2	% -1	% +1	% +2	% +3
Children with epilepsy should attend regular public school classes.	2.25 (1.47)	2.6	3.7	3.0	4.4	20.0	66.3
People often die from epileptic seizures.*	1.19 (2.04)	8.1	8.9	9.7	10.9	26.4	36.0
Epilepsy is a form of mental illness.*	2.00 (1.79)	5.6	4.5	4.1	7.4	13.0	65.4
People with epilepsy can safely operate machinery.	0.89 (2.13)	11.6	10.1	9.7	10.8	31.0	26.9
Insurance companies should deny insurance on the basis of a person's having epilepsy.*	2.48 (1.23)	1.9	1.9	1.9	5.2	14.1	75.1
In general, people with epilepsy are dangerous.*	2.70 (.87)	0.7	0.4	1.5	3.7	10.4	83.3
Most people with epilepsy should not drive automobiles.*	0.46 (2.38)	18.9	13.6	8.3	8.3	22.3	28.4
People with epilepsy should not have children.*	2.14 (1.55)	3.4	3.4	2.7	10.7	15.7	64.0
Having epilepsy makes others think less of you and your family.*	1.62 (2.09)	6.3	9.0	9.0	4.9	10.1	60.8
Epilepsy can affect any one, at any age.	1.78 (1.72)	5.4	3.9	4.6	13.5	24.7	47.9
Epileptics are usually less intelligent than most people.*	2.55 (1.15)	1.9	1.9	0.4	4.9	12.7	78.3
People with epilepsy can participate in any activity they choose.	1.72 (1.86)	4.6	8.7	4.6	6.1	26.2	49.8

Table 5, continued

ITEM	mean (s.d.)	% -3	% -2	% -1	% +1	% +2	% +3
People with epilepsy are often emotionally disturbed.*	1.99 (1.67)	3.0	6.7	3.0	9.3	18.3	59.7
Epileptic children in regular classes have negative effects on other children.*	1.60 (1.94)	4.1	9.8	8.3	5.6	21.8	50.4
When their seizures are controlled by medication, people with epilepsy are just like anyone else.	2.65 (0.96)	0.4	1.1	2.2	4.8	8.6	82.9
People with epilepsy are accident prone.*	1.85 (1.72)	1.9	7.6	7.2	8.3	20.5	54.5
Equal employment opportunities should be available to people with epilepsy.	2.63 (.92)	0.7	0.4	1.9	4.1	14.6	78.4
Parents should not expect of epileptic children what they expect of other children in the family.*	1.77 (1.99)	7.9	7.1	2.6	7.1	15.7	59.6
People with epilepsy are likely to show abnormal or violent behavior.*	1.95 (1.76)	1.5	6.7	7.5	7.1	18.4	58.8
Epilepsy may be contagious.*	2.81 (0.81)	1.1	0.0	1.1	1.5	4.9	91.4
People with epilepsy can cope with a forty-hour work week.	2.22 (1.49)	3.0	4.5	1.1	5.2	22.8	63.3
Epilepsy is a hereditary condition.*	0.34 (2.26)	15.7	22.0	13.1	10.6	18.6	19.9
It is possible to tell if a person has epilepsy by looking at them.*	2.61 (1.09)	0.7	2.2	1.9	3.3	8.9	82.9
Most epileptics lead normal lives.	2.51 (1.17)	0.7	3.3	1.5	1.9	17.8	74.7

Table 5, concluded

ITEM	mean (s.d.)	% -3	% -2	% -1	% +1	% +2	% +3
People with epilepsy should hide their condition.*	2.31 (1.38)	11	3.4	4.9	4.1	17.3	69.2
Epilepsy can usually be controlled so that a person does not have seizures.	2.38 (1.22)	11	2.6	2.6	3.0	25.6	65.0
People with epilepsy are more likely to be mentally retarded than other people.*	2.30 (1.46)	2.3	3.9	3.1	4.3	16.3	70.2

Note: Higher mean scores indicate more positive attitudes.

\* Indicates this item was recoded so that a positive score indicates a favorable response.

Perhaps the most disturbing findings of the survey, however, were on the following three items: (1) 24.3% of respondents agreed that having epilepsy makes others think less of you and your family; (2) 22.2% felt that epileptic children have negative effects on other children in the classroom; and (3) 17.6% agreed that parents should not expect of epileptic children what they expect of other children in the family.

Responses to most of the knowledge-based items were not very encouraging either. For example, almost one third of the subjects responded that people with epilepsy cannot safely operate machinery and over 40% felt epileptics should not be allowed to drive automobiles. More than one fourth of the respondents (26.7%) stated that people often die from epileptic seizures and over half believe epilepsy is a hereditary condition.

*Knowing People with Epilepsy.* Over half of the sample (59.4%) reported that they knew someone with epilepsy. Of these respondents, almost half (47.8%) said they knew only one person with epilepsy, 28.0% stated they knew 2 epileptics, only 12.4% knew three persons with epilepsy and the remaining respondents (11.8%) said they knew 4 or more people with epilepsy. One person in the sample reported having epilepsy, and 6.1% said an immediate family member (i.e., parent, child, sibling, or spouse) had epilepsy. Another 10% said that other family members had epilepsy, including grandparents, aunts or uncles, and nieces or nephews. The largest number of respondents described the person



they knew with epilepsy as a friend (42.9%), or an acquaintance (39.8% -- See Table 6).

Respondents who said they knew at least one person with epilepsy were asked to rate the person (on a scale of 1 to 10) on the following three items: (1) how capable this person is, (2) how dependable this person is, and (3) how stable this person is. The mean responses to these items are as follows: capable (mean = 7.40, s.d. = 1.84); dependable (mean = 7.29, s.d. = 2.07); and stable (mean = 7.20, s.d. = 2.01). These results suggest that individuals who know people with epilepsy, on the average, view them as capable, dependable and stable people.

Respondents were also asked to comment about any effect having epilepsy has on the epileptic's daily life. Half of the respondents felt that having epilepsy does affect the person's daily life, either somewhat (39.5%) or a great deal (10.5%). About one fourth of the respondents said that having epilepsy hardly affects this person's daily life at all, and a similar number felt it did not affect the person at all.

Responses to an open-ended question "In what ways has epilepsy affected their life" are summarized in Exhibit 1. As you can see, the largest categories of responses centered on how epilepsy affects day to day activities (e.g., cooking, driving, sports, taking medication) and self-concept (e.g., feeling vulnerable, embarrassed). Other issues raised by respondents include problems epileptics have with family, work and school.

Table 6

Relationship of Person with Epilepsy to Respondent  
Witnessing Seizures

RELATIONSHIP	N	%
Friend	69	42.9
Acquaintance	64	39.8
Cousin or Niece/Nephew	13	8.1
Sibling	5	3.1
Child	2	1.2
Spouse	2	1.2
Grandparent	2	1.2
Aunt/Uncle	2	1.2
Parent	1	0.6
Self	1	0.6

## Exhibit 1

Summary of Responses to Open-ended Question: "In what ways has epilepsy affected their life?"

CATEGORY OF RESPONSES	PERCENTAGE
<b>Daily Life Activities</b>	36.8%
<ul style="list-style-type: none"> <li>◆ can't cook</li> <li>◆ can't drive or has to be careful driving</li> <li>◆ careful with sports</li> <li>◆ generally are cautious and others often cautious with them (babied)</li> </ul>	
<b>Affects Social Life</b>	20.0%
<ul style="list-style-type: none"> <li>◆ marital problems</li> <li>◆ stigmatized as freakish by others</li> <li>◆ affects personal and sexual relationships</li> <li>◆ cannot drink alcohol</li> </ul>	
<b>Self-Perception/Self-Concept</b>	18.4%
<ul style="list-style-type: none"> <li>◆ epileptic feels vulnerable/insecure</li> <li>◆ frequent embarrassment</li> <li>◆ a lot of anxiety and stress for epileptic</li> <li>◆ negative self-concept</li> <li>◆ used as a crutch or excuse</li> </ul>	
<b>Problems with Work</b>	10.4%
<ul style="list-style-type: none"> <li>◆ limits choice of job/career</li> <li>◆ can't work overtime</li> <li>◆ sometimes can't work</li> </ul>	
<b>Education/School</b>	8.8%
<ul style="list-style-type: none"> <li>◆ other children don't understand</li> <li>◆ humiliation at school</li> <li>◆ treated differently by teachers and kids</li> <li>◆ miss a lot of school</li> </ul>	
<b>Family Problems</b>	5.6%
<ul style="list-style-type: none"> <li>◆ problems having family and raising children</li> <li>◆ treated differently within family</li> <li>◆ disrupts family, causes arguments</li> </ul>	

***Witnessing Seizures.*** Table 7 presents a crosstabulation of responses to the items: (1) Have you ever known anyone with epilepsy? and (2) Have you ever seen a seizure? As displayed below, 41.3% of the respondents reported that they knew someone with epilepsy and had seen a seizure at least once. Over one fourth of the sample (25.8%), however, said they have never known an epileptic and have never witnessed a seizure. In total, 56% of the respondents reported having seen an epileptic seizure, in person. Furthermore, three fourths of these respondents (77%) said they had seen a seizure more than once.

On the average, respondents described a seizure that occurred more than 10 years ago (mean = 12.8 years) in a public place (82.9%), for example, on the street, at school or in a restaurant (see Table 8). The seizure victim was described most frequently as a friend (17.1%) or acquaintance (37.5%) in his/her mid-twenties (mean age of victim = 24.4 years). More than half of the respondents discussed a male seizure victim (65.3%).

Respondents were asked to describe (open-ended) their experience during "the most recent time" they had seen a seizure. The responses were coded into nine categories. These findings are presented in Table 9. The most frequently mentioned descriptors were loss of consciousness, convulsions and twitching, all of which are associated with grand mal seizures. Symptoms associated with other types of seizures such as dizziness (11.6%) and strange repetitive movements (26.7%) were mentioned less frequently.

Table 7

Crosstabulation of Responses to Items: "Have you ever known anyone with epilepsy." and "Have you ever seen someone have a seizure?"

<b>KNOWN SOMEONE WITH EPILEPSY?</b>	<b>SEEN A SEIZURE?</b>		<b>TOTALS</b>
	<b>Yes</b>	<b>No</b>	
<b>Yes</b>	112 (41.3%)	49 (18.1%)	161 (59.4%)
<b>No</b>	40 (14.8%)	70 (25.8%)	110 (40.6%)
<b>TOTALS</b>	152 (56.1%)	119 (43.9%)	271

Table 8

Summary of Where Seizures Occurred

<b>PLACE WHERE SEIZURE OCCURRED</b>	<b>N</b>	<b>%</b>
Indoor public place (e.g., restaurant)	42	27.6
Outdoor public place (e.g, park)	41	27.0
At school	28	18.4
In a private home	26	17.1
At work	15	9.9

Table 9

Symptoms Mentioned by Respondents when Describing a Seizure

<b>SYMPTOM</b>	<b>Frequency</b>	<b>Percent of Respondents Mentioning</b>
Convulsions	98	65.3
Twitching	93	62.8
Loss of Consciousness	87	58.4
Strange Repetitive Movements	39	26.7
Eyes Rolling Back	36	24.5
Foaming at the Mouth/ Drooling	32	21.8
Dizziness	17	11.6
Incontinence	7	4.8
Other <sup>(1)</sup>	58	39.5

<sup>(1)</sup> Other includes: biting one's tongue, making strange noises, face turning blue.

Finally, respondents were asked to rate the experience of witnessing a seizure on the following items pertaining to the emotional impact of the event: (1) how frightening the experience was for the respondent, (2) how memorable the event is, (3) how disturbing witnessing this seizure was, and (4) how bizarre or freakish the experience was. Each of these items used a 4-point scale ranging from extremely (frightening, disturbing, etc.) to not at all (frightening, disturbing, etc.).

The overall responses to these items can be found in Table 10. Over half of the respondents (53.6%) rated the experience of observing a seizure as extremely bizarre, and 30.5% described this event as extremely frightening. A lesser number of respondents rated their experiences as extremely disturbing (22.5%) or extremely memorable (6.6%). About half of the respondents who answered these items, however, rated the experience as at least somewhat frightening (49.7%), disturbing (49.7%) or bizarre (68.8%).

Finally, these four items were averaged to yield a scale score for "emotional impact" to be used in further analyses. The Cronbach's alpha reliability coefficient for this four item scale is .69.

*Indirect Experience with Epilepsy.* Table 11 summarizes respondents' indirect experiences with epilepsy. Only about 28% of the sample said they had read about epilepsy in school books. Similar numbers of respondents said they had read about epilepsy in the newspaper (28.5%) or in pamphlets (30.5%).



Table 10

Responses to Items Assessing the Emotional Impact of Witnessing Seizures

ITEM	MEAN	S.D.	% not at all (1)	% not too (2)	% somewhat (3)	% extremely (4)
Frightening	2.41	1.13	30.5	19.2	29.1	21.2
Memorable <sup>(1)</sup>	2.91	.89	6.6	24.5	40.4	28.5
Disturbing	2.41	.98	22.5	27.2	37.1	13.2
Bizarre <sup>(2)</sup>	1.85	1.02	53.6	15.2	23.8	7.3

Note: Higher means indicate greater impact.

- (1) This item was actually worded: Would you say your memory of this event is extremely strong, somewhat strong, not too strong, or not at all strong?
- (2) This item was actually worded: Would you describe this experience as extremely bizarre or freakish, somewhat bizarre or freakish, not too bizarre or freakish, or not at all bizarre or freakish?

About 15% said they had read something about epilepsy in other books (e.g., novels), or other sources (e.g., encyclopedia). Almost half of the sample, however, categorized themselves as having read "almost nothing" about epilepsy. Only 9 people (5% of the respondents) felt they had read "quite a bit" about epilepsy. Slightly more than one third of the sample (35.5%) had seen a seizure on television or in a movie, and many of these respondents (66.0%) said this had happened more than once.

All respondents were also questioned about whether they had ever had discussions about epilepsy with family or friends. About half of the sample (52.8%) recalled having had at least one such discussion, and many of these respondents said they had discussed epilepsy informally on more than one occasion (an average of 4.8 times). Finally, respondents were asked to briefly describe what they talked about in such discussions. The results of this free-response item are summarized in Exhibit 2. Many respondents said they discussed the causes of seizures and epilepsy and the definition of a seizure as well as negative personal and social consequences of having epilepsy (e.g., misperceptions, negative attitudes, misdiagnosis).

Table 11

Summary of Respondents' Indirect Experience with Epilepsy

INDIRECT EXPERIENCE	FREQ. %	
<u>Reading</u>		
School Books	76	28.3
Magazines	116	43.0
Newspapers	77	28.5
Pamphlets	82	30.5
Other Books <sup>(1)</sup>	44	16.8
Other Sources <sup>(2)</sup>	40	14.9
<u>Seen a seizure on TV or in movies</u>	97	35.9
<u>Discussed epilepsy with family/friends</u>	142	52.8

(1) Includes, for example, novels.

(2) Includes, for example, encyclopedias or other reference books.

## Exhibit 2

Summary of Responses to Open-ended Item Concerning Discussions About Epilepsy with Family or Friends

CATEGORY OF RESPONSES	PERCENTAGE
<b>Negative Personal and Social Consequences of Having Seizures</b>	20.8%
<ul style="list-style-type: none"> <li>◆ mistaken perception of people with epilepsy (e.g., as drunk or on drugs)</li> <li>◆ misdiagnosis of epilepsy</li> <li>◆ how people cope with epilepsy</li> <li>◆ seizures resulting in injury</li> <li>◆ negative view of people with epilepsy</li> <li>◆ people with epilepsy not knowing it</li> <li>◆ what it would be like to have seizures, how a person feels/the experience of having a seizure</li> </ul>	
<b>What Causes Seizures and/or Epilepsy; What is a Seizure?</b>	16.8%
<ul style="list-style-type: none"> <li>◆ are people with epilepsy crazy?</li> <li>◆ is epilepsy hereditary?</li> <li>◆ why does someone have seizures?</li> </ul>	
<b>What To Do in the Event of a Seizure</b>	11.2%
<ul style="list-style-type: none"> <li>◆ should you put something in their mouth?</li> <li>◆ try to hold the person down</li> <li>◆ call an ambulance</li> </ul>	
<b>Questions about Causes, Treatments and/or Medication</b>	17.2%
<ul style="list-style-type: none"> <li>◆ will person die?</li> <li>◆ is epilepsy curable/treatable?</li> <li>◆ need for special diet</li> </ul>	
<b>What it is like to Witness a Seizure</b>	8.8%
<ul style="list-style-type: none"> <li>◆ emotions involved/the experience of seeing a seizure</li> <li>◆ description of feelings</li> </ul>	

## Exhibit 2, continued

CATEGORY OF RESPONSES	PERCENTAGE
<b>Caring for/Dealing with People with Epilepsy</b>	8.4%
♦ special treatment of epileptics because of their condition	
♦ responsibilities of parents with epileptic children	
♦ how person with epilepsy should behave	
<b>Types of Seizures, Symptoms and Effects</b>	7.6%
♦ questions about different types of seizures (e.g., grand mal/petit mal)	
♦ does epilepsy ever go away	
♦ how does it affect the body	
<b>What it Feels Like to have a Seizure</b>	2.8%

## Relationships Between Attitude and Experience Variables

The above discussion described the range of experience found among respondents in the sample. The following section presents the results of analyses investigating the relationship between various types of experience and attitudes.

The following major hypotheses were tested in this study:

- (1) Do individuals with only limited, but direct experience in the form of witnessing seizures have more negative attitudes than individuals with either greater ranges of experiences or only indirect experience?
- (2) Do respondents reporting they know people with epilepsy have more accepting views than people who do not personally know anyone with a seizure disorder?
- (3) Do individuals with direct experience of any kind have stronger attitudes than people with only indirect experience?
- (4) Do people with more experience with epilepsy have less negative attitudes?

Tests of these hypotheses are presented below. In addition, various demographic characteristics, including age, sex, education level and other personal or family handicaps were examined in conjunction with the experience and attitude variables.

*Hypothesis 1.* To test the first hypothesis (that individuals whose experience is limited to viewing seizures would have more negative attitudes than people with other types of experiences or no experience) respondents were classified as having either (1) limited but direct experience in the form of

witnessing seizures, or (2) any other level of experience with epilepsy (including those respondents with no direct experience). Respondents were classified as having limited but direct experience if they had never known anyone with epilepsy and reported seeing a seizure fewer than 5 times. Thirty-five respondents (12.9% of the total sample) were classified as falling into the limited, but direct experience category. The dependent variable for this analysis was the mean attitude scale score. An independent groups  $t$ -test was used to determine if there was a statistically significant difference in attitudes between the two experience groups defined above. The results of this analysis provide some evidence to suggest that respondents with limited but direct experience hold more negative attitudes towards people with epilepsy than those with other levels of experience, however, the results reached only a marginal level of statistical significance (means = 1.79 (s.d. = .74) and 2.01 (s.d. = .72);  $t$  (269) = -1.52,  $p$  < .07).

This hypothesis was based on the notion that witnessing seizures might have negative effects on viewers due to the possibly disturbing nature of the experience. Given that these findings reached only a marginal level of statistical significance, additional analyses were conducted to explore this hypothesis further. The first analysis examined whether those with limited but direct experience in the form of witnessing seizures differed from other respondents in the degree of emotional impact they reported about the most recent seizure they had seen. There was no significant difference between these two groups in the amount of emotional impact they reported ( $t$  (149) = 0.70, n.s.). It was also examined,

however, whether there was a difference in emotional impact between individuals who had witnessed a seizure only one time, and those with more extensive experience in this area. Responses to the item "how many times have you seen someone have a seizure" were coded into four categories: a) just once; b) a couple of times; c) a few times; or d) more than 5 times. A one-way Analysis of Variance, with the number of times respondent had seen a seizure as the independent variable revealed significant differences in the emotional impact attributed to the event of witnessing a seizure:  $F(3,147) = 4.87, p < .01$  (see Table 12). A follow-up Newman-Keuls test indicated that the group of respondents who reported having seen a seizure a more than 5 times described the experience as significantly less frightening, disturbing, memorable and bizarre. Finally, there was a significant correlation between attitudes and the emotional impact of witnessing seizures ( $r(151) = -.26, p < .01$ ), indicating that greater emotional impact is associated with more negative attitudes. These data suggest that the impact of witnessing seizures may be related to one's attitudes towards people with epilepsy. In sum, although the original hypothesis was supported only weakly, there is evidence to suggest that (1) witnessing seizures is an emotionally provocative event, and (2) this emotional impact is related to attitudes about the disorder.



Table 12

Mean Emotional Impact Scores by the Number of Times Respondent has Witnessed a Seizure

<b>NUMBER OF TIMES RESPONDENT HAS SEEN A SEIZURE</b>	<b>N</b>	<b>MEAN<sup>(1)</sup></b>	<b>S.D.</b>
Just once	46	2.53	.67
A couple of times (2 or 3)	45	2.49	.79
A few times (4 or 5)	23	2.53	.50
More than 5 times	37	2.01 <sup>(2)</sup>	.73

(1) One-way ANOVA  $F(3,147) = 4.87, p < .01$

(2) Newman-Keuls test indicates that this group's mean is significantly different from each of the other group means at the .05 level of significance.

***Hypothesis 2.*** The second hypothesis concerned whether people who know someone with epilepsy held more accepting attitudes than individuals who have never know anyone with epilepsy. To test this hypothesis, respondents were classified as either knowing someone with epilepsy or not. Then a  $t$ -test was used to examine whether those individuals acquainted with an epileptic had significantly more accepting views about the disorder. The findings from the analysis support this hypothesis. The mean attitude scores for those who know someone with epilepsy and those who do not are 2.06 and 1.86, respectively ( $t(269) = 2.05, p < .05$ ). In other words, individuals who reported knowing someone with epilepsy had significantly more accepting attitudes than respondents who have never known an epileptic individual. The degree of difference between these two groups, however, (0.2 on a 6 point scale) is slight.

***Hypothesis 3.*** It was also hypothesized that individuals with direct experience of any kind (i.e., seeing seizures or knowing people with epilepsy) would have stronger attitudes than persons with only indirect experience. First, an independent variable was created that classified respondents as having either some direct experience with epilepsy or not. Secondly, a dependent variable was created by taking the absolute value of each individual attitude item (e.g., a +3 and a -3 would both be recoded into 3) and then summing across all items to form a composite "attitude strength" score. The results of a  $t$ -test indicated no statistically reliable difference in attitude strength between individuals with direct

experience and those with only indirect experience (means = 2.44 and 2.42,  $t(269) = 0.51$ , n.s.).

*Hypothesis 4.* The last major hypothesis questions whether individuals with more experience of any kind have less negative attitudes towards people with epilepsy. To investigate this question, a "total experience" score was created by adding responses to four dichotomously scored (yes/no) items: (1) have you ever known anyone with epilepsy; (2) have you ever seen a seizure; (3) have you ever seen someone have an epileptic seizure on television or in a movie; and (4) do you remember ever discussing epilepsy with family or friends. The total experience score (KR-20 reliability coefficient = .32) was then correlated with the attitude scale score. Results uncovered a very weak but statistically significant association between the variables ( $r(271) = .12$ ,  $p < .05$ ).

Another way of exploring this question is to examine whether those with the least amount of experience (i.e., only indirect experience) have the most negative attitudes and those with the most experience have the least negative attitudes. A 2 x 2 Analysis of Variance was conducted with "known someone with epilepsy" (yes/no) and "witnessed a seizure" (yes/no) as the independent variables, and attitude score as the dependent variable (see Table 13). The only statistically significant findings from this analysis confirm that knowing someone with epilepsy is associated with holding positive attitudes ( $F(1,267) = 4.35$ ,  $p < .05$ ). If the hypothesis that people with more experience have less negative

Table 13

Mean Attitude Score by "Have you Ever Known Someone with Epilepsy?" and "Have you Ever Witnessed a Seizure?"

<b>KNOWN SOMEONE WITH EPILEPSY?</b>	<b>SEEN A SEIZURE?</b>	
	<b><u>Yes</u></b>	<b><u>No</u></b>
<b>Yes</b>	2.04 (112)	2.10 (49)
<b>No</b>	1.84 (40)	1.87 (70)

Notes: The attitude scale ranged from +3 to -3.

Cell n's are in parentheses.

attitudes was true, we would expect to find that the group with no direct experience (i.e., have never seen a seizure and have never known anyone with epilepsy) to have the least positive attitudes and the group with both types of direct experience to have the most positive attitudes. The fact that this analysis failed to uncover a significant interaction between these variables, however, suggests that the relationship between experience and attitudes is more complex. The weak correlation between total experience and attitudes described above, therefore, is probably a reflection of the large number of people in the sample who know someone with epilepsy and the positive effects that this type of experience has on attitudes.

### Demographic Analyses

Most of the additional analyses concern the relationship between various respondent demographics and attitudes towards people with epilepsy. Previous research has found a relationship between attitudes and demographic variables including age, sex and education level (Antonak & Rankin 1982; Gallup, 1987). Although no significant association was found between attitudes and age ( $r(268) = -.04$ , n.s.), a marginally significant association between sex of respondent and attitudes was found ( $t(267) = -1.61$ ,  $p < .06$ ), with the mean attitude score for women (2.03) being more accepting of epileptics than the mean score for men (1.87). These results are similar to Antonak and Rankin's (1982) findings that women in their sample had less negative views about epilepsy than male subjects.

Further analysis also uncovered a significant relationship between level of education and attitudes towards people with epilepsy. A one-way Analysis of Variance revealed a significant difference between respondents of various education levels in their attitudes towards people with epilepsy, with higher levels of education related to more accepting attitudes about epilepsy ( $F(7,260) = 4.92$ ,  $p < .01$ ) (see Table 14).

Analyses were also conducted to examine whether respondents who had worked in a job related to medicine held more accepting attitudes towards epileptics or felt differently about the experience of witnessing a seizure than those who had never worked in a field related to medicine. The results of a  $t$ -test examining whether respondents who had worked in a field related to medicine had more accepting attitudes than those who had not, found a marginally significant relationship in the predicted direction (means = 2.20 and 2.02, respectively,  $t(266) = 1.57$ ,  $p < .06$ ). A similar analysis with emotional impact as the dependent variable indicated that those who have worked in a medical field also reported significantly less emotional impact associated with witnessing seizures (means for those who have and have not worked in a medical job are 2.20 and 2.50, respectively;  $t(147) = -2.30$ ,  $p < .05$ ).

The final set of demographic analyses focused on whether respondents with a chronic health condition, or a family member with a chronic health condition held more accepting views about epilepsy than respondents without

Table 14

Mean Attitude Scores by Level of Education

EDUCATION LEVEL	MEAN <sup>(1)</sup>	N
Elementary School	1.27	5
Some High School	1.33	22
Graduated High School	1.97	71
Some College or A.A. Degree	1.97	75
Vocational School	2.13	6
Graduated College	2.18	49
Some Graduate Work	2.43	7
Holds Graduate Degree	2.24	33

<sup>(1)</sup> One-way ANOVA  $F(7,260) = 4.91, p < .01$ .

such characteristics. Respondents with a chronic health condition did not have significantly better attitudes than other respondents ( $t(265) = .80$ , n.s.), but they did report less emotional impact associated with viewing seizures than respondents without chronic health conditions (means = 2.14 and 2.44, respectively,  $t(146) = -1.92$ ,  $p < .05$ ).

Having a family member with a chronic health condition was also not related to respondent attitudes about epilepsy ( $t(263) = 1.28$ , n.s.), or to the amount of emotional impact associated with viewing seizures ( $t(145) = .73$ , n.s.).



## DISCUSSION

The discussion section is divided into four parts: (1) a summary of the hypotheses tested by this research, (2) a discussion of the implications of the findings, (3) the limitations of the present study, and (4) directions for future research in this area.

### Summary

The present study was designed to examine how various levels and types of experience with epilepsy are related to attitudes about the disorder. Based on social psychological theories of attitude formation and schema development, it was hypothesized that certain types of direct experience might have profound effects on attitudes about people with epilepsy. For example, it was predicted that individuals who personally know someone with epilepsy would have more accepting attitudes about the disorder than those who have never known someone with epilepsy. In contrast, it was hypothesized that viewing grand mal seizures might have negative effects on observers, due to the frightening and unpredictable nature of such events. People whose direct experience is limited to viewing such seizures were expected to have less positive opinions about epilepsy than those

with either greater ranges of experience or only indirect experience such as reading about epilepsy or seeing something on television. This is based on the notion that a single vivid experience can have more pronounced effects on a schema than more extensive experience associated with less psychological or emotional impact. In general, this research challenged the notion that the "more" experience someone has with epilepsy the "better" their attitudes will be concerning people with the disorder. A questionnaire was designed to investigate the above hypotheses about the link between experience and attitudes concerning epilepsy, as well as obtain accurate estimates of the general public's levels of experience with epilepsy.

The results of telephone interviews with approximately 270 adults in the Chicago area suggest that various attitudes about epilepsy are related to specific types of experiences. About 60% of the households contacted between June and October of 1989 completed a twenty minute survey on epilepsy. All households were randomly chosen for inclusion in the study and all calls were placed during evening hours Monday through Thursday or on Saturdays. The survey contained a 27-item measure of "attitudes towards people with epilepsy," a section on "knowing people with epilepsy," a section on "witnessing seizures," questions concerning other types of experience with epilepsy and, demographic information.

More than half of the survey respondents (56.0%) reported that they had witnessed an epileptic seizure and 59.4% of the sample stated they knew someone with epilepsy. When these variables were examined in relationship to

respondents' attitudes about epilepsy, the results suggest that not all types of experience with epilepsy are positive. Although respondents who know someone with epilepsy had significantly more accepting attitudes than those who are not personally acquainted with an epileptic, viewing seizures does not have a similar effect on respondents' attitudes. In fact, there is some evidence to suggest that witnessing seizures may be negatively related to attitudes.

To test the hypothesis that people with limited, but direct experience in the form of witnessing seizures would have less positive attitudes than people with either more experience or only indirect experience, respondents were identified who reported that their only direct experience with epilepsy was having witnessed a seizure "a few times" or less. This group was then compared to all other respondents on their attitudes towards people with epilepsy. Although only 35 people in the sample could be classified as having limited but direct experience in the form of witnessing seizures, this small group expressed more negative opinions about epilepsy than all other respondents in the sample.

To explore further the notion that misperception and negative public opinion about epilepsy is in some way related to viewing seizures, we examined the relationship between the emotional impact of viewing seizures and attitudes about the disorder. Respondents were asked to indicate how many times they had seen a seizure, and then were asked to describe the "most recent" seizure they had seen. They were also asked to rate how frightening, disturbing, memorable and bizarre this experience had been (i.e., ratings of emotional

impact). The results of the survey suggest that, in general, there appears to be a relationship between the emotional impact of viewing a seizure and respondents' overall attitude towards epilepsy. Respondents who rated the experience of viewing a seizure as frightening and disturbing were also more likely to hold negative attitudes about the disorder. The group of respondents classified as having limited but direct experience with epilepsy, however, did not rate the experience of viewing a seizure as any more distressing than the rest of the sample. Finally, we found a relationship between the number of times someone has seen a seizure and the emotional impact of the experience. Respondents who had seen a seizure "more than a few times" rated their most recent experience as having little emotional impact. In other words, the emotional impact of witnessing seizures tends to dissipate as the number of such experiences increases.

To review, although respondents with limited but direct experience in the form of witnessing seizures did not rate the experience of viewing a seizure as any more disturbing than other respondents, witnessing seizures does seem to be related to respondents' attitudes. When compared to respondents with either no direct experience or those who also know someone with epilepsy, those in the limited but direct experience group expressed more negative opinions. Therefore, it appears that any negative effects on attitudes due to witnessing seizures may be outweighed by the positive effects of knowing someone with epilepsy.

Another issue addressed by this research was whether having more experience of any kind was associated with more accepting attitudes about epilepsy. We found a very small but statistically significant positive correlation between respondents' total experience with epilepsy and their attitudes. Given that we failed to find corroborating evidence in the form of an interaction between knowing someone with epilepsy and viewing a seizure, it seems that only more of one type of experience -- knowing someone with epilepsy -- is related to having more accepting attitudes about the disorder. Greater amounts of other types of experience do not seem to contribute to more accepting opinions and may actually have a negative effect on one's attitude.

The hypothesis that tested whether people who had direct experience with epilepsy reported stronger attitudes about the disorder than individuals with only indirect experience was not supported. This may be due to several factors. First, epilepsy is probably not a very salient topic for most people and therefore, measuring the "strength" of respondent attitudes towards epilepsy among a sample of the general public by using the absolute value of points on the response scale may indicate nothing more than differences in tendencies to use various points on a response scale, rather than true differences in feelings about the subject. On the other hand, it may be that this method of measuring "strength" of respondent attitudes was not adequate. The use of only 3 points of reference for measuring the strength of respondent attitudes towards people with epilepsy (+3 to -3) may have obscured any relationship between strength and experience. Use of a larger

scale in a telephone interview, however, might have been problematic, as it is difficult for respondents to hold a large number of scale reference points in memory.

This hypothesis was based on previous research demonstrating differential strength associated with attitudes based on direct versus indirect experience (Fazio & Zanna, 1981). Fazio and Zanna (1981) hypothesize that direct experience may give a person greater amounts of information to work with in forming an attitude. Direct experience may also be processed differently than indirect experience by helping to focus attention on salient aspects of behavior. In addition, direct experience may make attitudes more accessible in memory. Therefore, measures of attitude accessibility and depth may be more appropriate to test hypotheses concerning the "strength" of attitudes based on direct experience. Finally, it may be that the hypothesized positive, linear relationship between attitude strength and direct experience does not exist.

Analyses were also conducted to examine whether various demographic variables were associated with more accepting attitudes towards people with epilepsy. Previous research (e.g., Antonak & Rankin, 1982; Caveness & Gallup, 1980) found that women had more accepting attitudes about epilepsy than men, and that level of education is positively correlated with attitudes. These findings were replicated in the present study. We also found that respondents who worked in a field related to medicine reported more accepting opinions and

described less emotional impact associated with witnessing seizures than the rest of the sample.

### Implications of the Present Research

The results of this study suggest that having more experience with epilepsy is not necessarily a good thing for the general public. The findings indicate that the two major types of experience people have with epilepsy (i.e., seeing seizures and knowing people with epilepsy) have different effects on attitudes about the disorder. First, it was found that respondents who know someone with epilepsy held more accepting views about epilepsy than those without such experience. These data point out the importance of disclosure by epileptics. In other words, it is important for people with epilepsy to make others aware of their condition and help to educate the general public about this often misunderstood illness. It is hypothesized that knowing people with epilepsy has positive effects on attitudes because it demonstrates that epileptics can and do lead normal lives. Therefore, programs or interventions designed to educate the general public about epilepsy might present epileptics holding various types of jobs and enjoying various types of recreation to reinforce the notion that people with epilepsy can lead normal lives and participate in a variety of activities. Involving successful people in the public eye (e.g., politicians, actors, athletes) in such campaigns would also help to make people aware that individuals with epilepsy can lead productive, healthy lives. Furthermore, doctors and other health professionals

who work with epileptics should encourage their patients to be open and honest about their illness. In general, these findings suggest that concealment of epilepsy may help epileptics avoid discrimination and cope with their epilepsy, but non-disclosure may also remove a necessary source of epilepsy education for the public.

The second major set of findings from this research indicate that: (1) witnessing an epileptic seizure can be an emotionally charged event, and (2) in the absence of other types of experiences, this emotional impact may have an effect on one's schema concerning people with epilepsy. Public opinion of epilepsy may be improved by educational programs stressing that the symptoms of an epileptic seizure (although vivid and frightening in nature) are not related to such associated stigma as mental illness, violence, lowered intelligence and other forms of abnormal behavior. It is important that educational programs stress why a seizure looks the way it does, i.e., due to electrical motor impairment, rather than psychological dysfunction. If the experience of witnessing seizures has negative effects on observers because the symptoms (e.g., convulsions, loss of motor control) are associated with other similar negative characteristics (e.g., tendency for violent, uncontrollable behavior), it is important to stress that the causes, symptoms and treatment of epilepsy are all physical and not psychological in nature. The results of the present study demonstrate that many people had a difficult time responding to knowledge-based questions (demonstrated by substantial amounts of missing data), but rarely had trouble



providing quick responses to attitude items. Overall, the responses to knowledge-based questions were also less accurate or positive than responses to pure attitude questions. Again, these results imply the general need for educational campaigns about epilepsy, and the specific need for focus on the physical nature of the illness.

### Limitations of the Study

The limitations of the present study generally concern the sample and the method of measurement of certain variables. First, the participants in this study (271 adults living in the Chicago metropolitan area) comprised an urban, largely female sample. Previous research has identified that individuals from urban areas (Gallup, 1987) and women (Antonak and Rankin, 1982) have significantly more accepting views about epilepsy than their rural and male counterparts. Therefore, the results of the present study may be somewhat biased towards more accepting attitudes concerning epilepsy. In other words, the findings from this study may be conservative estimates of the general public's attitudes towards people with epilepsy.

This study also reported slightly higher numbers of respondents who have ever seen a seizure (56.1%) or known anyone with epilepsy (59.4%) than found in prior research (see Canger & Cornaggia, 1985; Caveness and Gallup, 1980; Caveness, Meritt & Gallup, 1974; Iivanainen et al., 1980). If the sample is biased

towards "more experienced" respondents, the resulting relationships in the data may also be biased in some ways.

There are also several issues concerning the questionnaire that may have influenced the results. The questions involving witnessing seizures and knowing people with epilepsy were limited to the description of a single experience (i.e., the most recent time respondent had seen a seizure and the person with epilepsy who the respondent felt closest to or knows best). With regards to knowing people with epilepsy, describing only the person with epilepsy the individual felt closest to may present a picture where epileptics' capabilities, problems, coping, etc., in general are overstated. Similarly, by limiting the description of witnessing seizures to the most recent experience, we forfeited the opportunity to explore how reactions to viewing seizures changes with repeated exposure.

As discussed above, the measure of strength of respondents' attitudes towards people with epilepsy may have been problematic. The method of using absolute value scores on the attitude scale may have assessed the magnitude or valence of respondents' attitudes towards persons with epilepsy (i.e., degree of favorability or unfavorability), however, it may be that other dimensions warrant specific attention. For example, the importance (i.e., centrality), and salience of attitudes may be more relevant measures for this type of study than the degree of favorability (Oskamp, 1977). To measure the importance of attitudes towards people with epilepsy, questions addressing willingness to help a person with epilepsy or donate one's time to an epilepsy organization might be used.

### Directions for Future Research

The findings from this study suggest that not all types of experience with epilepsy have positive effects on attitudes about the disorder. However, the most we can conclude from surveys of the general public is that relationships among experience and attitude variables exist. To explore the relationship between witnessing seizures and the formation of attitudes towards people with epilepsy, controlled, experimental studies assessing the link between attitudes and experience should be conducted. Experimental research will allow examination of causal links between these types of variables.

Further research in this area might also focus on the general public's awareness of and experiences with various types of epilepsy. This and other studies have demonstrated that the average person thinks of epilepsy in terms of a "grand mal" seizure. There are millions of people, however, who have very different forms of epilepsy. The label of epilepsy, therefore, often implies a more serious condition than is actually the case. This overgeneralization of what epileptic seizures are like may also bring with it a host of misattributions.

In addition, future studies should go beyond investigating correlates of attitudes towards people with epilepsy and begin to examine factors related to negative behaviors towards people with epilepsy (e.g., discrimination or not aiding seizure victims). Again, Fazio and Zannas' (1981) research suggests that direct experience with an attitude object makes an attitude more accessible, and that such accessibility is related to greater attitude-behavior consistency. Therefore,

future work should address how direct experience is related to behaviors towards people with epilepsy, and to attitude-behavior consistency.

Although this study focused on the cognitive component of attitudes, other components of attitudes towards people with epilepsy (e.g., purely emotional reactions such as fear, pity or empathy) might also be explored in further research.

Finally, as discussed above, the findings from this study have implications for the design of educational programs about epilepsy. Future research should also focus on the implementation and evaluation of such programs.

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## **APPENDIX**

Introduction and Informed Consent

(Note: Interviewer reads anything in CAPS to respondent).

HELLO, MY NAME IS \_\_\_\_\_ AND I AM A RESEARCHER FROM LOYOLA UNIVERSITY. WE ARE INTERVIEWING PEOPLE OVER THE AGE OF 18 CONCERNING THEIR OPINIONS ABOUT EPILEPSY. WOULD YOU HELP US WITH OUR RESEARCH AND ANSWER SOME QUESTIONS?

If yes, continue introduction and then go on to survey.

If no, ask if you could call them back sometime later in the week or next week.

If person is not 18 or older, ask to speak with an adult.

THE SURVEY TAKES TEN TO FIFTEEN MINUTES TO COMPLETE AND YOUR RESPONSES WILL BE COMPLETELY CONFIDENTIAL. YOU WERE SELECTED FOR INTERVIEWING BY A METHOD FOR RANDOMLY CHOOSING HOUSEHOLDS. IF THERE ARE ANY QUESTIONS YOU DON'T CARE TO ANSWER, WE'LL JUST SKIP OVER THEM. YOU ARE ALSO FREE TO END THE INTERVIEW AT ANY TIME.

Interview Information

- |    |   |                 |
|----|---|-----------------|
| 1) | Interviewer number  | C1: _____       |
|    | 1 -- Claudia  |                 |
|    | 2 -- Martha   |                 |
|    | 3 -- Ed   |                 |
|    | 4 -- Joe  |                 |
|    | 5 -- Elke   |                 |
|    | 6 -- Greg   |                 |
| 2) | Date of interview (mm/dd)                                   | C2 - C5: _____  |
| 3) | Starting time of interview (e.g., 0630 for 6:30)            | C6 - C9: _____  |
| 4) | Number of callbacks (maximum # = 5)<br>(from sample sheets) | C10: _____      |
| 5) | ID # (phone # + 1)      (743-6104 becomes 7436105)          | C11 -C17: _____ |
| 6) | Order of questionnaire                                      | C18: _____      |
|    | 1 -- experience/attitude                                    |                 |
|    | 2 -- attitude/experience                                    |                 |

Experience with Epilepsy

I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT ANY EXPERIENCE YOU HAVE WITH EPILEPSY. WE ARE INTERESTED IN HEARING ABOUT ANY OF YOUR EXPERIENCES -- THINGS LIKE TALKING WITH PEOPLE, READING THINGS, AND SEEING THINGS ON TV OR IN MOVIES ARE INCLUDED, NOT JUST KNOWING PEOPLE WITH EPILEPSY OR SEEING SEIZURES. SOME PEOPLE HAVE HAD LITTLE OR NO EXPERIENCE WITH EPILEPSY AND OTHER PEOPLE ARE ABLE TO TELL US ABOUT MORE THAN ONE TYPE OF EXPERIENCE. IT IS IMPORTANT THAT YOU TRY TO RECALL ALL OF YOUR EXPERIENCES, EVEN EXPERIENCES FROM CHILDHOOD OR INFORMAL DISCUSSIONS.

Section I: Knowing People with Epilepsy

1) HAVE YOU EVER KNOWN ANYONE WITH EPILEPSY? C19: \_\_\_\_\_

- 1 -- Yes
- 2 -- No (go on to section II: Witnessing seizures)

2) HOW MANY PEOPLE HAVE YOU KNOWN WITH EPILEPSY? \_\_\_\_\_ (fill in) C20 -C21: \_\_\_\_\_

\*\*\*\* If they know just one person go right to #3.

If they know more than one person, read the following statement first:

NOW I WOULD LIKE TO ASK YOU A SERIES OF QUESTIONS ABOUT THE PERSON YOU KNOW WITH EPILEPSY WHO YOU ARE CLOSEST TO OR KNOW BEST.

3) WHAT IS THIS PERSON'S RELATIONSHIP TO YOU? C22: \_\_\_\_\_

- 1 -- parent
- 2 -- child
- 3 -- spouse
- 4 -- grandparent
- 5 -- cousin or niece/nephew
- 6 -- aunt/uncle
- 7 -- friend
- 8 -- an acquaintance (e.g., co-worker, classmate)
- 9 -- sibling

4) FOR HOW LONG HAVE YOU KNOWN THIS PERSON? \_\_\_\_\_ C23 -C24: \_\_\_\_\_  
(in years; 6 years = 06)

5) IS THIS PERSON MALE OR FEMALE? C25: \_\_\_\_\_

- 1 -- male
- 2 -- female

- 6) **HOW OLD IS THIS PERSON?** \_\_\_\_\_ C26 -C27: \_\_\_\_\_  
(in years; 6 years = 06)
- 7) **ON A SCALE OF 1-10, WHERE 1=THE LEAST CAPABLE PERSON YOU'VE EVER KNOWN, AND 10=THE MOST CAPABLE PERSON YOU'VE EVER KNOWN, HOW CAPABLE WOULD YOU SAY THIS PERSON IS?** C28: \_\_\_\_\_  
(0=no answer or can't respond)
- 8) **ON A SCALE OF 1-10, WHERE 1=THE LEAST DEPENDABLE PERSON YOU'VE EVER KNOWN, AND 10=THE MOST DEPENDABLE PERSON YOU'VE EVER KNOWN, HOW DEPENDABLE WOULD YOU SAY THIS PERSON IS?** C29: \_\_\_\_\_  
(0=no answer or can't respond)
- 9) **ON A SCALE OF 1-10, WHERE 1=THE LEAST STABLE PERSON YOU'VE EVER KNOWN, AND 10=THE MOST STABLE PERSON YOU'VE EVER KNOWN, HOW STABLE WOULD YOU SAY THIS PERSON IS?** C30: \_\_\_\_\_  
(0=no answer or can't respond)
- 10) **WOULD YOU SAY HAVING EPILEPSY AFFECTS THIS PERSON'S DAILY LIFE:** C31: \_\_\_\_\_
- 1 -- A GREAT DEAL  
2 -- SOMEWHAT  
3 -- HARDLY AT ALL  
4 -- NOT AT ALL (go on to Section II: Witnessing seizures)  
5 -- don't know (do not read aloud)
- 11) **IN WHAT WAYS HAS EPILEPSY AFFECTED THEIR LIFE?**  
(open-ended: code later)

-----  
 Section II: Witnessing seizures  
 -----

1) HAVE YOU EVER HAPPENED TO SEE SOMEONE HAVE AN EPILEPTIC SEIZURE, IN PERSON? (not on TV, etc) C32: \_\_\_\_\_

- 1 -- Yes
- 2 -- No (go on to Section III: Indirect experience)

2) HOW MANY TIMES HAVE YOU SEEN SOMEONE HAVE A SEIZURE? C33: \_\_\_\_\_

- 1 -- more than 5
- 2 -- a few (4 or 5)
- 3 -- a couple (2 or 3)
- 4 -- just once

\*\*\*\* If they have seen just one seizure, go right on to #3.

If they have seen more than one seizure, read this statement first:

NOW I WOULD LIKE TO ASK YOU A SERIES OF QUESTIONS ABOUT  
THE MOST RECENT TIME YOU HAVE SEEN A SEIZURE.

3) HOW LONG AGO DID THIS HAPPEN? (in years) C34 -C35: \_\_\_\_\_

4) WHAT WAS YOUR RELATIONSHIP TO THE PERSON HAVING THE SEIZURE? C36: \_\_\_\_\_

- 1 -- parent
- 2 -- child
- 3 -- spouse
- 4 -- grandparent
- 5 -- cousin or niece/nephew
- 6 -- aunt/uncle
- 7 -- friend
- 8 -- an acquaintance (e.g., co-worker, classmate)
- 9 -- sibling
- 0 -- I did not know them

5) WHERE DID THE SEIZURE OCCUR? C37: \_\_\_\_\_

- 1 -- In a home
- 2 -- On the street or other outside public place (e.g. park)
- 3 -- At school
- 4 -- At work
- 5 -- Other indoor public place (e.g., restaurant, library)
- 6 -- I don't remember

6) APPROXIMATELY HOW OLD WAS THE PERSON HAVING THE SEIZURE? (in years) C38 -C39: \_\_\_\_\_

7) WAS THIS PERSON MALE OR FEMALE? C40: \_\_\_\_\_  
 1 -- male  
 2 -- female

8) NOW I WOULD LIKE YOU TO DESCRIBE WHAT YOU SAW:

*(Note: Interviewer record response then code later, where 1=yes, 2=no)*

1 -- loss of consciousness	C41: _____
2 -- convulsions	C42: _____
3 -- twitching	C43: _____
4 -- dizziness	C44: _____
5 -- foaming at the mouth/drooling	C45: _____
6 -- incontinence	C46: _____
7 -- strange repetitive movements	C47: _____
8 -- eyes rolling back	C48: _____
9 -- other (specify _____)	C49: _____

9) WOULD YOU DESCRIBE THIS EXPERIENCE AS: C50: \_\_\_\_\_

*(Note: Interviewer reads responses aloud to respondents)*

1 -- EXTREMELY FRIGHTENING  
 2 -- SOMEWHAT FRIGHTENING  
 3 -- NOT TOO FRIGHTENING  
 4 -- NOT AT ALL FRIGHTENING

10) WOULD YOU SAY YOUR MEMORY OF THIS EVENT IS: C51: \_\_\_\_\_

*(Note: Interviewer reads responses aloud to respondents)*

1 -- EXTREMELY STRONG  
 2 -- SOMEWHAT STRONG  
 3 -- NOT TOO STRONG  
 4 -- NOT AT ALL STRONG

11) WOULD YOU DESCRIBE THIS EXPERIENCE AS:

C52: \_\_\_\_\_

*(Note: Interviewer reads responses aloud to respondents)*

- 1 -- EXTREMELY DISTURBING
- 2 -- SOMEWHAT DISTURBING
- 3 -- NOT TOO DISTURBING
- 4 -- NOT AT ALL DISTURBING

12) WOULD YOU DESCRIBE THIS EXPERIENCE AS:

C53: \_\_\_\_\_

*(Note: Interviewer reads responses aloud to respondents)*

- 1 -- EXTREMELY BIZARRE OR FREAKISH
- 2 -- SOMEWHAT BIZARRE
- 3 -- NOT TOO BIZARRE
- 4 -- NOT AT ALL BIZARRE

---

**Section III: Indirect experience with epilepsy**

---

1) HAVE YOU EVER READ ANYTHING ABOUT EPILEPSY IN:

a) SCHOOL BOOKS

C54: \_\_\_\_\_

1 -- yes

2 -- no

b) ANY OTHER BOOKS (specify \_\_\_\_\_)

C55: \_\_\_\_\_

1 -- yes

2 -- no

c) MAGAZINES

C56: \_\_\_\_\_

1 -- yes

2 -- no

d) NEWSPAPER

C57: \_\_\_\_\_

1 -- yes

2 -- no

e) PAMPHLETS

C58: \_\_\_\_\_

1 -- yes

2 -- no

f) ANY OTHER SOURCES (please specify)

C59: \_\_\_\_\_

1 -- yes

2 -- no

2) WOULD YOU SAY THAT YOU'VE READ:

C60: \_\_\_\_\_

*(Note: Interviewer reads responses aloud to respondents)*

1 -- QUITE A BIT

2 -- A FAIR AMOUNT

3 -- JUST A LITTLE BIT

4 -- ALMOST NOTHING

3) HAVE YOU EVER SEEN SOMEONE HAVE AN EPILEPTIC SEIZURE  
ON TELEVISION OR IN A MOVIE?

C61: \_\_\_\_\_

1 -- yes

2 -- no (go on to question 6)



- 4) CAN YOU ESTIMATE HOW MANY TIMES YOU HAVE SEEN A SEIZURE ON TV OR IN A MOVIE? (open-ended) C62 -C63: \_\_\_\_\_  
(e.g., 2 = 02)

\*\*\* If they respond just once, go right to # 5

If they have seen a seizure more than once, ask #5 about the most recent time they have seen a seizure on tv or in a movie.

- 5) DO YOU RECALL HOW OLD YOU WERE? (in years) C64 -C65: \_\_\_\_\_

- 6) DO YOU REMEMBER EVER DISCUSSING EPILEPSY WITH YOUR FAMILY OR FRIENDS? C66: \_\_\_\_\_

1 -- yes  
2 -- no (go on to next page)

- 7) CAN YOU ESTIMATE HOW MANY TIMES YOU HAVE DISCUSSED EPILEPSY? (open-ended) C67 -C68: \_\_\_\_\_

- 8) CAN YOU BRIEFLY DESCRIBE WHAT YOU TALKED ABOUT?

Attitudes Towards People with Epilepsy

I AM GOING TO READ A SERIES OF STATEMENTS ABOUT EPILEPSY AND WOULD LIKE YOU TO TELL ME TO WHAT EXTENT YOU AGREE OR DISAGREE WITH EACH OF THE STATEMENTS.

Interviewers: 1) Ask respondent if they agree or disagree with each statement. Place an A or D next to the statement. If respondent replies "don't know" or "can't decide" etc. write down the response and code it as 0.

2) Follow up each agree/disagree response with the question about how strongly they agree or disagree as it appears in statement #1. Code agree responses as +1 to +3, and code disagree responses as -1 to -3. Do not read the 1-3 as positive or negative to respondents.

DO YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENT?

- |     |  |                |
|-----|--|----------------|
| 1)  | CHILDREN WITH EPILEPSY SHOULD ATTEND REGULAR PUBLIC SCHOOL CLASSES.  | C1 - C2: _____ |
|     | ON A SCALE OF 1-3, WHERE 1=SLIGHTLY AGREE (OR DISAGREE) AND 3=STRONGLY AGREE (OR DISAGREE), HOW STRONGLY DO YOU AGREE (OR DISAGREE) WITH THIS STATEMENT? |                |
| 2)  | PEOPLE OFTEN DIE FROM EPILEPTIC SEIZURES.  | C3 - C4: _____ |
| 3)  | EPILEPSY IS A FORM OF MENTAL ILLNESS.  | C5 - C6: _____ |
| 4)  | PEOPLE WITH EPILEPSY CAN SAFELY OPERATE MACHINERY.   | C7 - C8: _____ |
| 5)  | INSURANCE COMPANIES SHOULD DENY INSURANCE ON THE BASIS OF A PERSON'S HAVING EPILEPSY.  | C9 -C10: _____ |
| 6)  | IN GENERAL, PEOPLE WITH EPILEPSY ARE DANGEROUS.  | C11-C12: _____ |
| 7)  | MOST PEOPLE WITH EPILEPSY SHOULD NOT DRIVE AUTOMOBILES.  | C13-C14: _____ |
| 8)  | PEOPLE WITH EPILEPSY SHOULD NOT HAVE CHILDREN.   | C15-C16: _____ |
| 9)  | HAVING EPILEPSY MAKES OTHERS THINK LESS OF YOU AND YOUR FAMILY.  | C17-C18: _____ |
| 10) | EPILEPSY CAN AFFECT ANY ONE, AT ANY AGE.   | C19-C20: _____ |
| 11) | EPILEPTICS ARE USUALLY LESS INTELLIGIENT THAN MOST PEOPLE.   | C21-C22: _____ |

- 12) PEOPLE WITH EPILEPSY CAN PARTICIPATE IN ANY ACTIVITY THEY CHOOSE. C23-C24: \_\_\_\_\_
- 13) PEOPLE WITH EPILEPSY ARE OFTEN EMOTIONALLY DISTURBED. C25-C26: \_\_\_\_\_
- 14) EPILEPTIC CHILDREN IN REGULAR CLASSES HAVE NEGATIVE EFFECTS ON OTHER CHILDREN. C27-C28: \_\_\_\_\_
- 15) WHEN THEIR SEIZURES ARE CONTROLLED BY MEDICATION, PEOPLE WITH EPILEPSY ARE JUST LIKE ANYONE ELSE. C29-C30: \_\_\_\_\_
- 16) PEOPLE WITH EPILEPSY ARE ACCIDENT PRONE. C31-C32: \_\_\_\_\_
- 17) EQUAL EMPLOYMENT OPPORTUNITIES SHOULD BE AVAILABLE TO PEOPLE WITH EPILEPSY. C33-C34: \_\_\_\_\_
- 18) PARENTS SHOULD NOT EXPECT OF EPILEPTIC CHILDREN WHAT THEY EXPECT OF OTHER CHILDREN IN THE FAMILY. C35-C36: \_\_\_\_\_
- 19) PEOPLE WITH EPILEPSY ARE LIKELY TO SHOW ABNORMAL OR VIOLENT BEHAVIOR. C37-C38: \_\_\_\_\_
- 20) EPILEPSY MAY BE CONTAGIOUS. C39-C40: \_\_\_\_\_
- 21) PEOPLE WITH EPILEPSY CAN COPE WITH A FORTY-HOUR WORK WEEK. C41-C42: \_\_\_\_\_
- 22) EPILEPSY IS A HEREDITARY CONDITION. (passed on to children from their parents) C43-C44: \_\_\_\_\_
- 23) IT IS POSSIBLE TO TELL IF A PERSON HAS EPILEPSY BY LOOKING AT THEM. C45-C46: \_\_\_\_\_
- 24) MOST EPILEPTICS LEAD NORMAL LIVES. C47-C48: \_\_\_\_\_
- 25) PEOPLE WITH EPILEPSY SHOULD HIDE THEIR CONDITION. C49-C50: \_\_\_\_\_
- 26) EPILEPSY CAN USUALLY BE CONTROLLED SO THAT A PERSON DOESN'T HAVE SEIZURES. C51-C52: \_\_\_\_\_
- 27) PEOPLE WITH EPILEPSY ARE MORE LIKELY TO BE MENTALLY RETARDED THAN OTHER PEOPLE. C53-C54: \_\_\_\_\_

Demographic Section

FINALLY, I WOULD LIKE TO ASK YOU JUST A FEW QUESTIONS ABOUT YOURSELF TO HELP US ANALYZE THE SURVEY RESULTS.

1) WHAT WAS YOUR AGE AT YOUR LAST BIRTHDAY? (in years) C1 - C2: \_\_\_\_\_

2) WHAT IS THE LAST GRADE OF SCHOOL YOU COMPLETED? C3: \_\_\_\_\_

- 1 -- elementary school
- 2 -- some high school
- 3 -- graduated high school
- 4 -- some college or A.A. degree
- 5 -- vocational school
- 6 -- graduated college
- 7 -- some graduate work
- 8 -- holds graduate degree

3) HAVE YOU EVER WORKED IN ANY FIELD RELATED TO MEDICINE? C4: \_\_\_\_\_

- 1 -- yes
- 2 -- no (go on to question 5)

4) WHAT TYPE OF JOB DID YOU HAVE? \_\_\_\_\_ C5: \_\_\_\_\_

5) DO YOU HAVE ANY CHRONIC HEALTH CONDITIONS? C6 - C7: \_\_\_\_\_

- 1 -- yes (specify \_\_\_\_\_)
- 2 -- no

6) DOES ANYONE IN YOUR FAMILY HAVE ANY CHRONIC HEALTH CONDITIONS? C8 - C9: \_\_\_\_\_

- 1 -- yes (specify \_\_\_\_\_)
- 2 -- no

\*\*\*\*\*  
 THIS CONCLUDES THE INTERVIEW. THANKS VERY MUCH FOR YOUR HELP.  
 \*\*\*\*\*

7) Sex of respondent (interviewer code) C10: \_\_\_\_\_

- 1 -- male
- 2 -- female

8) Ending time of interview (9:45 = 0945) C11 -C12: \_\_\_\_\_

9) Interviewer comments

(Please comment on things such as: respondent had language problems or hearing problems or seemed to be rushed to get through the interview, etc.)

## APPROVAL SHEET

The dissertation submitted by Claudia Lampman has been read and approved by the following Committee:

Dr. Linda Heath, Director  
Professor, Psychology, Loyola

Dr. John Edwards  
Associate Professor, Psychology, Loyola

Dr. Emil Posavac  
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The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

3/22/90

Date

Linda Heath

Director's Signature