

THE EVERYDAY LIVES OF ADOLESCENT GIRLS WITH EPILEPSY:
A QUALITATIVE DESCRIPTION

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DEDICATION

For my husband, James Lachlan MacLeod, who encouraged me to begin this endeavor, cheered me on every step of the way, tolerated my absences from home to study and research, persuaded me to continue when I wanted to quit, and never stopped believing I would finish. For you, my love, with gratitude.

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ABSTRACT

Jessica S. MacLeod

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QUALITATIVE DESCRIPTION

This study is a qualitative description of the everyday lives of adolescent girls with epilepsy. The primary purpose of the research was to determine whether or not elements of stigma were present in narratives about participants' day-to-day living. The researcher used open-ended and semi-structured interview techniques in a series of interviews with four adolescent girls with epilepsy. Elements of stigma were present in some of the constructed themes; however, the researcher also uncovered other unexpected themes. Themes constructed by the researcher included:

1) I Am Like Everyone Else (Except for my Seizures); 2) There are Worse Things than Epilepsy; 3) My Parents Trust Me; 4) Am I Having a Seizure?; 5) Bullying Because of Seizures; 6) Bullying Because of Something other than Seizures; 7) Coping with Bullying; 8) Academic Difficulties; 9) Disclosure Management; 10) Seizures are Scary to Have and to See; and 11) If I have a Seizure, Don't Attract Attention to Me! The researcher considers topics thought to be important to adolescents with epilepsy about which the participants kept silent. The researcher makes suggestions about how the research can be used to improve health care practice and guide educational policies for

adolescent students with epilepsy. Based on the findings, the researcher suggests areas for future research in nursing and educational policy.

Melinda M. Swenson, PhD, APRN, FAANP, ANEF, Chair

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CHAPTER 1

INTRODUCTION AND BACKGROUND

Epilepsy is a common neurological disorder characterized by seizures— abnormal electrical impulses in the brain that cause involuntary bodily movement, sensation, or awareness (Centers for Disease Control [CDC], n.d.). Epilepsy can occur at any time of life, but the incidence is highest in childhood. In their international meta-analysis of incidence studies of epilepsy, Kostopoulos, van Merode, Kessels, de Krom, and Knottnerus (2002) report a median incidence of 82.2 cases of epilepsy per 100,000 children. The most recent United States epidemiological data estimate that 30,000 children and adolescents are diagnosed with this condition each year (Hauser, 1994).

Though epilepsy is relatively common, children and adolescents can have significant problems associated with their illness. Children with epilepsy have high rates of depression, documented in two studies at 25% and 26% respectively (Dunn, Austin, & Huster, 1999; Ettinger et al., 1998). Adolescents with epilepsy have an increased risk of experiencing behavioral and psychiatric disorders when compared to their healthy peers or adolescents with other chronic illnesses such as diabetes, asthma, or cardiac disease (Davies, Heyman, & Goodman, 2003; Dunn, & Austin, 1999; McDermott, Mani, & Krishnaswami, 1995; Rutter, Graham, & Yule, 1970). Adolescent girls with epilepsy may be especially at risk for poor psychosocial outcomes. Girls with epilepsy have higher anxiety levels, more behavioral problems, and lower social competence than

their male peers (Austin, Dunn, & Huster, 2000; Austin, Risinger, & Beckett, 1992; Funderburk, McCormick, & Austin, 2007; McDermott et al., 1995).

A preliminary reading of the literature on children and adolescents with epilepsy raises important questions for me. Epilepsy is common. Why are children and adolescents diagnosed with this disorder more anxious and depressed than those with other non-neurological disorders like diabetes or cardiac conditions? More specifically, why are adolescent girls with epilepsy most at risk for poor psychosocial outcomes? A comprehensive examination of these broad questions is well beyond the scope of any one research project. Teams of researchers from multiple disciplines will continue to study the complex interplay between variables such as potential neuronal damage from seizures, the role of anti-seizure medication and side-effects, cognitive factors, and family coping factors (Plioplys, Dunn, & Caplan, 2007).

As I read the literature on adolescents with epilepsy, I became interested in the idea that the social stigma that accompanies epilepsy could be one factor that contributes to the poor psychosocial outcomes of adolescent girls with this chronic illness (MacLeod & Austin, 2003; Westbrook, Bauman, & Shinnar, 1992). Peer groups influence whether a condition carries a stigma. Perhaps the difference between male and female adolescent peer groups could partially explain why epilepsy seems to be a particularly devastating diagnosis for adolescent girls.

Throughout history, epilepsy often has been represented in scientific and lay literature as a disease with an associated social stigma that is psychologically

damaging to the person with the disease. This sentiment is so strong that in recent years the World Health Organization, the CDC, and the Epilepsy Foundation have embarked on campaigns to try to increase awareness about epilepsy and decrease the social stigma that seems to accompany this disease (Austin, Shafer, & Deering, 2002; CDC, n.d.; Reynolds, 2001). Some people with epilepsy report that coping with social stigma is the greatest challenge that they face (Scambler & Hopkins, 1990).

Despite the historical and conventional wisdom that epilepsy carries with it a social stigma, empirical research with adolescents with epilepsy remains limited and equivocal (MacLeod & Austin, 2003). Some studies report that stigma is a problem for adolescents with epilepsy, while other research does not. Critiques of existing empirical research with adolescents with epilepsy have called attention to the lack of use of current stigma theory, as well as concerns with measurement of this complex concept (Jacoby, Snape, & Baker, 2005; MacLeod & Austin, 2003).

Stigma is a complex concept difficult to measure with traditional instrumentation. Any investigation that attends carefully to stigma theory should consider the influence of individual as well as cultural and societal factors. Researchers must attend to instances of actual discrimination and prejudice as well as individual perceptions of rejection. The way in which people choose to control or disclose information about a stigmatizing condition or to actively challenge and reject stigmatizing processes are also vital to a comprehensive understanding of this phenomenon (Link, & Phelan, 2001a). Link and Phelan

(2001a) have argued that in many empirical research studies, the modest effects of stigma on “life chances” such as employment, income, and housing are erroneous, resulting from incomplete measurement of the concept (p. 363). They argue that rather than measuring the effect of a single piece of the stigma puzzle on one outcome, we need a comprehensive, multifaceted, and multilevel investigation to fully understand the influence of stigma in a person’s life (Link, & Phelan, 2001a).

We need more research to gain a better understanding of the influence of stigma in the lives of adolescents with epilepsy, especially girls. A new instrument called the Child Stigma Scale has shown content and construct validity and internal consistency reliability (Austin, MacLeod, Dunn, Shen, & Perkins, 2004). In addition, others have suggested the use of unstructured, open-ended interviews to provide a way for adolescents to talk freely about issues of concern in their day-to-day lives (Jacoby et al., 2005; MacLeod, & Austin, 2003). Encouraging conversation in a minimally structured way might help adolescent girls to articulate subtle ways that they perceive or experience stigma related to epilepsy. On the other hand, adolescent girls may talk about their everyday living and may not feel stigmatized at all. Either way, talking with adolescent girls in a minimally structured way and constructing a comprehensive description of their everyday living will broaden our understanding of what it is like to live with epilepsy. This information is useful on its own, or could be used to guide further research. Considering the above, the research question for this

project is what are the daily life experiences of adolescent girls with epilepsy that may or may not reflect stigma?

Purpose

The primary purpose of this research is to construct a vivid description of the everyday experiences of adolescent girls with epilepsy. Narratives may or may not reflect stigma. Direct measurement instruments that ask questions of vulnerable teens may not yet be sensitive enough to pick up the subtle and contextual nature of stigma, however, the Child Stigma Scale is showing promise (Austin et al., 2004). A secondary purpose therefore will be to administer this short instrument to measure perceived stigma. I do not intend to use the narrative data to corroborate or refute the accuracy of the individual Child Stigma Scale scores. Instead, I will use the Child Stigma Scale scores as an additional source of data for the qualitative description. It will be interesting to compare and contrast the scores on the scale with the narrative data as a way to flesh out or better understand the stories of these young women. Techniques that allow adolescents to speak freely about common, everyday experiences may reveal subtleties about living as an adolescent with epilepsy. Feelings of stigmatization may or may not be reflected in these stories. My aim is to listen to the stories of these young women and create a comprehensive description of their everyday living that reflects their voices, viewpoints, and concerns.

CHAPTER 2

LITERATURE REVIEW

The purpose of this research study is to describe the everyday living of adolescent girls with epilepsy. I will pay close attention to the narratives of the young women whom I interview, and I hope to be able to construct themes based upon shared experiences of the young women. Before actually conducting the interviews and studying the narratives of the participants, it is impossible to know what will be important to the daily living of these young women with epilepsy. I do, however, have a hunch that elements of stigma could be included in their stories. Because of the many ways in which it can be experienced or felt, I do not want to miss subtle expressions or instances of stigma. I therefore conducted a preliminary, rather than exhaustive, literature review to gather background information on stigma theory and familiarize myself with existing research on stigma in adolescents with epilepsy. After I analyze the data, I will return to the literature and read about the issues and themes that I have constructed. I will place my findings within a context of what is already known about these yet-to-be-determined themes.

I conducted the literature review on stigma theory and on stigma in adolescents with epilepsy in order to provide a context in which to read the narratives of the participants. I acknowledge that my understanding of stigma theory will be a “sensitizing concept” (Charmaz, 2003, p. 85) meant to draw my attention to possible presentations of stigma if and when they appear in the participants’ stories. It is also crucial that I do not try to force the stories of these

young women into preconceived theoretical categories, because it is entirely possible that elements of stigma will be conspicuously absent. I must try to be attentive and reflective in my thinking and concentrate on the actual words that are in the narratives (van Manen, 2006). I propose to engage in modified bracketing, which is not an un-learning of background knowledge, but a recognition that I must reflect on what I already know about stigma theory and how that will influence what I see in the text and how I develop a meaningful summary (Janesick, 2000). After I analyze and describe the everyday living of these young women, it will be necessary for me to go back to the literature to decide how my findings fit with what we already know about adolescent girls with epilepsy. Some of my findings may be expected, and some may be more of a surprise. Either way, I will endeavor to place my findings in a context of existing research literature to promote a deeper understanding of the everyday living of adolescent girls with epilepsy.

Stigma

The definition of stigma that informs this paper is a more recent broad description (Link, & Phelan, 2001b) that is based on early, seminal work on the concept of stigma (Goffman, 1963). Link and Phelan (2001b) conceptualized stigma as an actual or perceived loss of status and power as a result of separation from the general population because of a characteristic that has been culturally defined as different and undesirable. Stigmatization includes not only overt acts of discrimination, but also disapproval and rejection from others. A

person might also experience stigma through the expectation of how others will react to a perceived difference (Goffman, 1963; Link, & Phelan, 2001b).

Cultural Norms and Individual Perceptions

Using the above definition to study stigma, it becomes apparent that there are two facets that influence whether an individual perceives stigma in his or her life. First, a social group must decide that an attribute is undesirable and therefore potentially stigmatizing. Culture is therefore an important consideration when studying stigma. Indeed, a multi-national European survey of over 5,000 adults with epilepsy demonstrated significant differences in felt stigma by country of residence (Buck, Jacoby, Baker, Ley, & Steen, 1999). The authors propose that a country's public attitude toward epilepsy influences whether or not its residents with epilepsy feel stigmatized. Attempting to study stigma in adolescents with epilepsy becomes even more complex, as it can be argued that adolescents belong not only to the societal group of their parents, but also to a cultural subset of a peer adolescent group (Brown, 2004; Brown, Eicher, & Petrie, 1986). Adolescents form peer groups that exert influence over individual attitudes and behaviors (Brown, 2004). The result is groups of adolescents with homogenized attitudes about what constitutes desirable or undesirable characteristics or behaviors.

Individual factors are the second facet that may influence feelings of stigma in a person with epilepsy. These may include personal attitudes, beliefs, or coping mechanisms. Belonging to a group that societal norms label as different and undesirable does not mean that an individual accepts this label for

the self. In one study, women with chronic mental health problems recognized that society might hold negative perceptions of people with mental health problems, although they rejected these perceptions as pertaining to them individually. Interestingly, although the women did not accept the negative labels, they still worried that they would experience discrimination or negative reactions because of others' faulty or invalid perceptions (Camp, Finlay, & Lyons, 2002).

Enacted Stigma and Felt Stigma

Enacted stigma and felt stigma are concepts that have been defined in research literature. Enacted stigma is defined as an instance of demonstrable discrimination as a direct result of having epilepsy. Felt stigma is defined as feeling different because of having epilepsy, even if overt discrimination has not occurred (Scambler, & Hopkins, 1986). It has been proposed that even without instances of direct, appreciable discrimination, people with epilepsy may feel stigmatized (Jacoby, 1994; Scambler & Hopkins, 1986). Mechanisms by which this occurs include self-labeling as well as prior sensitization by a parent to feel shame about epilepsy (Scambler, & Hopkins, 1986). As I study the narratives of the young women in this research study, it is important that I pay attention to enacted stigma and felt stigma.

Discredited or Discreditable

The dichotomy of enacted versus felt stigma is possible with a disease such as epilepsy, because it does not manifest with a permanent physical marker. Although a person with epilepsy may feel different from others, it is impossible to tell by looking at someone whether that person has epilepsy or not.

Today's medical treatment of epilepsy is quite advanced, and many people with epilepsy remain seizure-free for long periods of time (Shinnar, & Pellock, 2002). This characteristic of epilepsy corresponds to what has been described as the visibility or invisibility of a chronic illness (Joachim, & Acorn, 2000). Epilepsy is somewhat unique in that it has characteristics of both a visible and an invisible chronic illness. When a person with epilepsy is seizure-free, their disease is invisible. However, there is the chance that a seizure may occur, which is usually a visible occurrence. (Some types of seizures, including absence or partial seizures may not be visible or recognizable as such to those who witness them.)

In the parlance of stigma theory, those with an immediately recognizable, visible difference have been described as discredited, while those with a less obvious difference are discreditable (Goffman, 1963). People with epilepsy must cope with the ambiguity of having a disease that is mostly invisible, but with the potential for becoming visible during a seizure. People with epilepsy walk a fine line between being judged by others as discredited or discreditable. It has been proposed that one way in which people with epilepsy cope with this ambiguity is through disclosure management strategies (Westbrook et al., 1992). Some people with epilepsy may choose to disclose their epilepsy to friends, employers, and teachers, while others may keep their diagnosis a secret (Jacoby, 1994; Joachim, & Acorn, 2000; Westbrook et al., 1992). Disclosure management strategies may influence whether the stigma experienced by people with epilepsy is enacted or felt. For example, one study reported that although only 2% of subjects could name a specific instance of discrimination at work in the past two

years, 32% felt that their epilepsy made it more difficult for them to secure employment (Jacoby, 1994). Although not asked specifically, some of the respondents clarified this apparent discrepancy, stating that they kept their epilepsy secret out of fear of possible discriminatory action due to their diagnosis.

Research on Stigma in Adolescents with Epilepsy

There is a limited amount of published research on the experiences of stigma in adolescents with epilepsy. The findings from the research are equivocal; however, the results can be used to direct future study.

One study tested stigma theory directly with a sample of adolescents with epilepsy (Westbrook et al., 1992). The authors developed a model based on stigma theory and hypothesized six specific relationships among stigma attributes (seizure type, seizure frequency, and duration of epilepsy), perceived stigma, management of disclosure, and self-esteem (Westbrook et al., 1992). The study included a cross-sectional sample of 64 adolescents, ages 12 to 20, recruited from hospital-based outpatient clinics or private physicians' offices affiliated with a large, metropolitan teaching hospital. Adolescents were excluded from the sample if they had other chronic illnesses in addition to epilepsy, were mentally retarded, or had abnormal neurological exams. Adolescents filled out three self-report questionnaires that demonstrated adequate reliability and validity. The questionnaires measured perceived stigma, disclosure management, and self-esteem. Information about seizure type, frequency, and duration of epilepsy was gathered from the subject's neurologist, chart review, and parent and subject self-report.

Results from the study indicated that most of the adolescents did not feel stigmatized (Westbrook et al., 1992). For example, 66% reported that they never thought that having epilepsy affected whether people wanted to be friends with them or not. Most (60%) reported that they never thought that having epilepsy affected whether people liked them or not, and 69% reported that they never thought that having epilepsy affected whether or not they were invited on a date or to a party. Most of the adolescents (89%) answered yes when asked if they thought that people with epilepsy could have sexual relationships just like people without epilepsy.

On the other hand, about one third of this sample did perceive at least some stigma. Researchers should also pay attention to the fact that more than half of the sample (53%) kept their epilepsy a secret from others at least some of the time, and 70% of the adolescents in the sample rarely or never talked to others about their epilepsy. It is possible that the adolescents had not experienced stigmatizing encounters with others because they had not disclosed their diagnosis of epilepsy, or if they had, they talked about it infrequently.

Other important findings from the study were that a higher level of perceived stigma was correlated with poorer self-esteem, and those ages 12 to 16 had higher mean perceived stigma scores than those adolescents ages 17 to 20. Variables not significantly related to perceived stigma included seizure type, seizure frequency, seizure duration, gender, and racial or ethnic identity (Westbrook et al., 1992). It is interesting that in this study gender was not related to perceived stigma.

The authors acknowledged threats to the study's internal validity, including the possibility that the small sample size was statistically inadequate to find significant, predicted results (Westbrook et al., 1992). The authors also acknowledged that coping strategies or self-perceptions of adolescents might moderate the relationship between stigma and self-esteem.

Findings from this study may not be applicable to all adolescents with epilepsy (Westbrook et al., 1992). The cross-sectional sample of adolescents was drawn from specialized epilepsy clinics and neurology offices affiliated with a metropolitan teaching hospital. This sample may represent adolescents with epilepsy refractory to treatment, and may exclude adolescents who are cared for in rural communities by primary care providers. Because teaching hospitals often have specialized health care programs and social services, the adolescents in this sample may have benefited from the support of clinical nurse specialists and social workers with expertise in adaptation problems of adolescents with epilepsy. This specialized education and support may have helped the adolescents to cope with living with epilepsy, perhaps resulting in fewer feelings of stigma.

The authors do not discuss how their study results could be explained by stigma theory, nor do they indicate how this study influences or changes the theory that serves as the basis for their model (Westbrook et al., 1992). In returning to classic stigma theory (Goffman, 1963), some important considerations become apparent. The adolescents reported not feeling stigmatized, although they also kept their diagnosis a secret from most others.

Decisions about disclosure—to whom and in what circumstance—are a central part of stigma theory. Secret keeping is an important concept when studying stigma.

In a different, but related study on adolescent social functioning, Westbrook, Silver, Coupey, and Shinnar (1991) found significant differences in disclosure management between adolescents with epilepsy and adolescents with other chronic illnesses. Only 15 % of the adolescents with epilepsy said that all of their friends knew about their disorder, as compared to 59% of the adolescents with other chronic illnesses. Of the adolescents with other chronic illnesses, 70% said that all of their teachers knew of their disorder, while 65% of the adolescents with epilepsy said that only some of their teachers were aware of their diagnosis (Westbrook et al., 1991).

In this study (Westbrook et al., 1991) the adolescents with epilepsy clearly kept their diagnosis a secret more often than adolescents with other chronic illnesses. It is not clear *why* this was the case. There were significant differences in the groups with respect to age, age at onset of diagnosis, duration of illness, and hospitalization rates. These basic differences between the two groups may have influenced the findings. Also, the comparison group of adolescents was heterogeneous with respect to their illnesses. Adolescents in that group had been diagnosed with asthma, diabetes, sickle-cell anemia, inflammatory bowel disease, lupus, congenital hip deformity, hemophilia, rheumatic heart disease, endocrine disorders, and arthritis. Some of these chronic illnesses may have an associated social stigma and some may not. Some of these illnesses are visible to others, while some are invisible. Out of all these chronic illnesses, it is

interesting that adolescents with epilepsy most often kept their diagnosis a secret. This might be because epilepsy holds the most associated stigma. It is also possible that findings were watered-down due to the heterogeneous comparison sample. It would be interesting to compare disclosure management strategies in adolescents with epilepsy to adolescents with a chronic illness that has similar visibility /invisibility and potential for stigmatization such as inflammatory bowel disease.

Indeed, adolescents with epilepsy may keep silent about their diagnosis because of a peer social culture that rejects differences of any kind. In fact, a recent, large multi-site survey describes a number of harmful perceptions about epilepsy held by adolescents in the general population (Austin, Shafer et al., 2002). This survey was completed by 19,441 adolescents in public and private schools in various urban, suburban, and rural areas of the United States. Survey respondents were balanced in gender and ethnically diverse. In the literature, this survey did not have a reported title. For ease of reading this literature review, I will call it the Austin survey.

Results from the Austin survey indicated that adolescents in the general population were not familiar with epilepsy, had little correct knowledge about epilepsy and seizures, and held perceptions about epilepsy that reflected stigma. It reported that only about half (52%) of adolescents remembered hearing or reading about epilepsy. It also illuminated several misconceptions that adolescents in the general population held about epilepsy, including the fact that only 51% knew for sure that epilepsy was not contagious and less than a third

knew that epilepsy was not a form of mental illness. Adolescents held beliefs that may indicate how the social environment leads to feelings of stigma in their peers with epilepsy. For example, 40% of the adolescents were not sure if people with epilepsy were dangerous or not, and about half (46%) did not know if it was possible to tell if someone has epilepsy by looking at him or her (Austin, Shafer et al., 2002). Only 24% of the adolescents were sure that their peers with epilepsy were *not* more likely to get picked on or bullied than others. Only 31% of adolescents surveyed reported that they would date a person with epilepsy, and fewer than half said that if they had epilepsy, they would tell their friends (Austin, Shafer et al., 2002).

Strengths of the Austin survey include the large sample size, as well as the diverse geographical locations from which respondents were drawn. Limitations of the study relate to the nature of the quantitative data collected in surveys, in that the researcher could not explore the reasons for particular beliefs.

The Austin survey is a beginning description of the peer social culture in which adolescents with epilepsy conduct their everyday lives. Culturally defined disapproval is a hallmark of a stigmatizing condition. This survey provides insight into the attitudes, perceptions, and beliefs that are held by adolescents in the general population in regard to epilepsy. An understanding of this culture is essential when investigating stigma in adolescents with epilepsy.

Other research on adolescents with epilepsy has not tested stigma theory or treated stigma as the primary variable of concern in the research. Instead, the

following studies have conceptualized stigma as a variable that could contribute to various other health outcomes in adolescents with epilepsy, such as health-related quality of life, depression, and social functioning (Cramer et al., 1999; Devinsky et al., 1999; Dunn, Austin, & Huster, 1999; Funderburk et al., 2007; Stevanovic, 2007).

Cramer et al. (1999) included a stigma subscale in their development of the QOLIE-AD-48, an instrument to measure quality of life in adolescents with epilepsy. A seven-member advisory panel of experts developed the scale from existing measures, a review of the literature specific to adolescents with epilepsy, and focus groups of adolescents with epilepsy. The scale was then administered to 197 adolescents ages 11 to 17 recruited from 17 epilepsy centers in the United States, 3 epilepsy centers in Canada, and 3 private practices. Adolescents were excluded from the sample if they had had epilepsy surgery in the past year, if they had had a change in their medication in the past four months, or if they were taking another medication that had additional central nervous system effects.

The QOLIE-AD-48 was found to have adequate content and construct validity, as well as adequate reliability (Cramer et al., 1999). A threat to this study's external validity was that most subjects were recruited from epilepsy centers, perhaps indicating that their epilepsy required referral to specialized clinics. There were therefore no participants treated in the community by a primary health care provider.

The concept of stigma emerged as an important factor in health-related quality of life in adolescents with epilepsy. The stigma subscale was strongly

correlated ($r = 0.64$) with the overall QOLIE-AD-48 score. In this sample, the mean stigma subscale score was 71.3, with a standard deviation of 22.0, and a possible range from 1 to 100. Higher scores indicated better functioning. The average overall QOLIE-AD-48 score was also relatively high at 67.7, with a standard deviation of 17.3 and a possible range from 16 to 98. Therefore, many adolescents in this sample reported a relatively high overall quality of life with relatively low levels of stigma. These results suggest that adolescents with epilepsy are faring well psychologically; however, there could be alternate explanations.

As previously noted, adolescents who receive care from epilepsy centers may be receiving specialized medical, educational, and supportive assistance from physicians, clinical nurse specialists, social workers, and psychologists that helps them to cope better with the issues that they face as people with epilepsy. The results from this sample should not be generalized to adolescents who receive their medical care outside of epilepsy centers. Additionally, although mean scores for the stigma subscale and the overall QOLIE-AD-48 were relatively high, there was also a wide standard deviation of scores. This indicates that at least some of the participants experienced stigma and reported a poorer health-related quality of life. It would have been interesting to talk to some of those participants to explore their experiences further.

Using the QOLIE-AD-48 and multiple regression analyses, Devinsky et al. (1999) examined potential risk factors for poor health-related quality of life (HRQOL) in adolescents with epilepsy. Results indicated that the six-item stigma

subscale of the QOLIE-AD-48 explained 22% of the variance in overall HRQOL scores. Variables significantly associated with more stigma, as well as lower overall HRQOL scores were lower socioeconomic status and participation in special education classes. There also were trends for stigma to be associated with more physician visits per year and longer duration of epilepsy. Because Devinsky et al. (1999) used the data from the Cramer et al. (1999) instrument development of the QOLIE-AD-48 to test factors associates with poor HRQOL in adolescents with epilepsy, the threat to external validity is the same.

Stevanovic (2007) used the QOLIE-AD-48 to measure HRQOL in Serbian adolescents with well-controlled epilepsy. The 71 participants in this study had been seizure free for at least one year. Average QOLIE-AD-48 scores were higher than those reported in the Cramer et al. (1999) study, with the mean score for boys 83.9 (SD 10.56) and the mean score for girls 83.06 (SD 12.92). Higher scores indicate better HRQOL. The high scores could indicate that the adolescents were generally positive about their health-related quality of life. On the other hand, Stevanovic (2007) reports that although average scores were high, there was a wide variance between individual subject scores. He suggests that individualized approaches to evaluating health-related quality of life in adolescents with epilepsy may yield a better understanding of self-perception and well-being in this group.

Using regression analysis, the author reports some other interesting results (Stevanovic, 2007). Those who were fearful about having another seizure reported lower health-related quality of life. Although boys and girls did not differ

on their total scores for HRQOL, girls reported that epilepsy had more impact on their lives. In general, in the Stevanovic (2007) study, adolescents reported negatively on the attitude toward epilepsy scale.

One study focused on attitude toward epilepsy as a potential mediating variable between perceived stigma and mental health outcomes of children with epilepsy (Funderburk et al., 2007). The authors used measurements of self-concept, social competence, and behavior problems to describe mental health outcomes. A total of 173 boys and girls ages 9 through 14 participated in the study. The children in the study had epilepsy for at least 6 months and were on at least one seizure medication. Children with a history of another chronic condition, progressive brain disorder, or diagnosis of mental retardation were excluded from this study. Participants were recruited from school nurses, private neurology practices, and neurology clinics in the Indianapolis area. The researchers used instruments found previously to have adequate reliability and validity to measure the child's perception of stigma, the child's attitude toward illness, self-concept, behavior problems, and social competence (Funderburk et al., 2007). Children were also divided into active or inactive seizure status.

Funderburk et al. (2007) found that attitude toward epilepsy partially mediates the relationship between perceived stigma and mental health outcomes. Specifically, attitude mediates the relationship between stigma and self-concept and behavior problems, but not social competence. The authors report the difficulty in trying to discretely and distinctly measure the similar concepts of children's attitude toward epilepsy and stigma perceptions. Indeed,

Link and Phelan (2001a) include personal attitude in their definition of individual factors that influence perceptions of stigma. A descriptive study that asks about what it is like to live as an adolescent with epilepsy might provide rich data that further elucidates these concepts.

Another important result from the Funderburk et al. (2007) study is that female gender was associated with lower social competence than the male participants. At first read, the reported lower social competence of girls seemed to be yet another reason why I needed to talk to young women with epilepsy; to find out why they were faring less well than boys. As I went back to the research report, I noted that social competence was measured by a scale that is completed by parents. Parents report on three areas, including social, activity, and school. Parents report activities of the child, how much time she spends doing each one and how well she does each one compared to others her own age (Funderburk et al., 2007). This type of proxy measurement has flaws. For example, perhaps parents have different social expectations for boys and girls. Perhaps parents feel more comfortable rating boys higher in comparison to peers. After all, United States culture rewards competitiveness in boys and conformity in girls. This finding is intriguing; and may reveal elements of a *culture* that is more responsible for causing stigma than the chronic illness of epilepsy.

Through their use of unstructured focus groups of Scottish adolescents with epilepsy, McEwan, Espie, Metcalfe, Brodie, and Wilson (2004) sought to describe the experience of having epilepsy in adolescence and broaden the understanding of quality of life in this population. Although framed in the context

of adolescent developmental issues and peer acceptance, instances of felt and enacted stigma were apparent. The majority of adolescents (19 out of 22) articulated worrying about bullying or social isolation. Eight adolescents recalled instances of enacted stigma, or actual rejection by others, while 11 others feared rejection from peers (felt stigma). Decisions regarding disclosure, including whom and when to tell about a diagnosis of epilepsy, were included in the larger theme "Identity Formation Issues." Seven teenagers talked about a social environment of prejudice because the general population lacked knowledge and understanding about epilepsy.

Instances of felt and enacted stigma, disclosure management strategies, and the recognition of a social culture that deems epilepsy to be an undesirable characteristic are hallmark characteristics of a stigmatized condition. Although McEwan, Espie, Metcalf, Brodie et al. (2004) were interested in the general experiences of adolescents with epilepsy; specific concerns that reflected stigma were prevalent and notable. Perhaps the open-ended, unstructured way in which they asked about living with epilepsy was the key in uncovering some of these sensitive, contextual, and personal feelings.

Admi and Shaham (2007) used a combination of unstructured and more focused interviewing techniques to describe further the *ordinary people theory* originally generated through interviews with American youth with cystic fibrosis. Admi (1995) describes the ordinary people theory as an alternative model to psychological, medical, or deviance models of chronic illness. For Admi (1995) people with chronic illness are ordinary and normal and are coping with

extraordinary situations. In the current study, Admi and Shaham (2007) interviewed 14 Israeli adolescents and young adults with epilepsy. The authors report that most participants described themselves as being normal, with epilepsy not the central focus of their lives. The authors describe the participants as ordinary young people dealing with the extraordinary situation of managing medical treatments, dealing with seizures, and trying to prevent their health problems from influencing their future (Admi & Shaham, 2007).

Although the participants in this research study described themselves as ordinary, and Admi and Shaham (2007) concluded that epilepsy was not central to the lives of their participants, some of the direct quotes in the research report contradict this conclusion. For example, one participant had been fired from his job because of his epilepsy. He stated, "If there are seizures, there isn't work; if there aren't seizures, there is work" (Admi & Shaham, 2007, p. 1184). Losing one's employment because of a chronic illness is significant. Another participant said, "Inside I know. I feel that something is eating away at me because I am keeping a secret" (Admi & Shaham, 2007, p. 1184). Some participants thought that others had erroneous perceptions of people with epilepsy, and that these perceptions contributed to personal feelings of shame. Others had more positive and open relationships with others regarding their epilepsy. It might be important to find out why some people keep their epilepsy a secret from others and why others don't, and which strategy seems better at strengthening positive mental health outcomes.

Indeed, Admi and Shaham (2007) described the complexities of how their study's participants managed information about epilepsy. The authors describe an individualized approach to managing information about epilepsy. Audience selection (whom to tell), situational factors, and telling strategies all were factors as participants described to whom they spoke about their epilepsy. Importantly, information management seemed to change over time as adolescents matured into young adults with perhaps a better understanding of their disease and its possible impact on their lives.

I think that the stigma associated with epilepsy is potentially problematic for adolescent girls with epilepsy; and may contribute to poorer mental health outcomes than their peers without this chronic illness. Elements of stigma theory, such as disclosure management strategies, are apparent in the Admi and Shaham (2007) study of Israeli adolescents and young adults with epilepsy. Some of the Scottish adolescents in the McEwan, Espie, Metcalf, Brodie et al. (2004) study had actually experienced rejection; while others worried about being bullied. In their large survey of the general adolescent population, Austin et al. (2002) found a peer adolescent culture that held attitudes and beliefs about epilepsy that could contribute to the stigmatization of this chronic illness. Funderburk et al. (2007) found that attitude toward epilepsy partially mediates the relationship between stigma and mental health outcomes in young people with epilepsy.

Although other research has not found stigma to be an important factor in the lives of adolescents with epilepsy, I think there is enough evidence to warrant

further investigation (Cramer et al., 1999; Stevanovic, 2007; Westbrook et al., 1992). To date, there is no published qualitative description of what it is like to live in the United States as an adolescent girl with epilepsy. An important part of stigma theory is culture, so experiences of adolescent girls in the United States may differ from that of Scottish or Israeli young people with epilepsy (Buck et al., 1999).

After conducting a preliminary review of the literature on adolescent girls with epilepsy, I am left with the following impressions:

- Epilepsy is a common neurological disorder, yet it has an associated social stigma that can be psychologically damaging.
- Adolescent girls with epilepsy are especially at risk for poor psychosocial outcomes.
- Stigma is a complex concept.
 - The presence or absence of stigma is influenced by cultural norms and individual perceptions.
 - Stigma can be *enacted* through overt discrimination or rejection.
 - Stigma can be *felt* by a person who has never been exposed to actual rejection, bullying, or discrimination.
 - The invisibility or visibility of a chronic illness or condition influences whether it is stigmatized or not.
 - Disclosure management strategies are often used by people in order to minimize stigma.

- Some research reports that stigma is a problem for adolescents with epilepsy, other research does not.
- Adolescents with epilepsy are less likely to talk about their illness than adolescents with other chronic illnesses.
- An adolescent's attitude toward his or her epilepsy seems important in mental health outcomes.
- In Scotland and Israel, adolescents and young adults with epilepsy have experienced both enacted and felt stigma.
- In the United States, adolescents know very little about epilepsy. Much of the time, their perceptions about epilepsy are factually wrong and potentially hurtful to those with epilepsy.

A teenage girl with epilepsy living in the United States is at risk for experiencing stigma. Many of the necessary elements are present. She is growing up in a peer culture that misunderstands her disease. She is likely to keep her disease a secret from others or discuss it infrequently. Her peers in other countries have described actual encounters with bullies and discrimination. Although it seems possible and even likely that adolescent girls with epilepsy experience stigma and its negative consequences, existing quantitative research remains equivocal. Because stigma can occur in complex and subtle ways, current instrumentation may not be sophisticated enough to detect its presence. A detailed, vivid description of the daily lives of adolescent girls with epilepsy is needed to investigate whether stigma is a presence in their lives or not. This project asks: what are the everyday experiences of adolescent girls with

epilepsy? I used interview techniques that encouraged participants to express concerns in a minimally structured way. I asked the young women to talk about their everyday living, rather than asking them to talk specifically about either epilepsy or stigma. It is my hope that the findings from this research will help nurses and others who work in health care to better understand what it is like to live as an adolescent girl with epilepsy, regardless if stigma is apparent in their lives or not.

CHAPTER 3

METHODOLOGY

Approach

Naturalistic inquiry and qualitative description are approaches suited to finding out about the everyday experiences of adolescent girls with epilepsy. Naturalistic inquiry, or a naturalistic approach, is not a unique research method. Rather, it is a philosophical stance that suggests that phenomena are best studied in their natural setting where complexities and interactions with other phenomenon abound. Using a naturalistic approach, the researcher studies a phenomenon in its own surroundings, and inductively tries to come to a deep understanding of a phenomenon as it occurs in the messy and complex real world (Denzin, & Lincoln, 2000; Lincoln, & Guba, 1985).

For this research project, I wanted to describe the everyday living of adolescent girls with epilepsy. I wanted to understand how their chronic illness “fit” into the daily living of an adolescent girl. Would epilepsy and seizures dominate the day, or act as mere background noise in a teenager’s raucous school, homework, activity, friend, boy-filled life? Could this differ day-to-day and person-to-person?

I used both open-ended and semi-structured interview techniques which I hoped would allow the young participants to talk about things that mattered to them. Despite my hunch that elements of stigma would punctuate their stories, I did not want prematurely to assume this to be true. I acknowledge that I felt tension between the purest tenets of a naturalistic approach and the reality that I

have already researched stigma theory. Some researchers who promote qualitative research methods suggest no literature review should be undertaken until after the data are collected and analyzed (Morse, 1994; Streubert, & Carpenter, 1999). The rationale for this delay is to avoid the influence of current knowledge or ways of thinking on what is potentially new knowledge. After all, naturalistic inquiry is supposed to be an inductive exercise.

My rationale for engaging in a preliminary literature review on stigma in the lives of adolescent girls with epilepsy was two-fold. First, I think that the literature review has exposed gaps in our understanding of the possible role of stigma in their lives (Sandelowski, & Barroso, 2003). Secondly I think that the equivocal findings of the few studies that exist may be due to a lack of attention to the subtleties of how stigma can manifest in the lives of these young women. I needed to be able to place my findings within a context of what is already known about being an adolescent girl with epilepsy. This includes a working knowledge of how epilepsy has been historically associated with stigma, the elements of stigma theory, and expected adolescent development. All of this background information may help me to identify “threads” of stigma theory, if it is present and problematic for these girls (Charmaz, 2004, p. 985).

Qualitative Description as a Form of Naturalistic Inquiry

Qualitative description closely follows the tenets of naturalistic inquiry, and is used when a researcher wants to describe a phenomenon, rather than explain it (Sandelowski, 2000). I used this method because I wanted to describe the everyday living of adolescent girls with epilepsy in their own words and voice

(Guba, & Lincoln, 2005). Lack of time and funding did not allow me to engage in “fieldwork” or the opportunity to observe the participants for stretches of time in their everyday surroundings. Instead, I used open-ended and semi-structured interview techniques to allow these young women to talk about their day. Through their words and descriptions I constructed a thorough description of what it is like for them to live with epilepsy. I tried to stay as close to the participants’ words as I could, however some interpretation was necessary to represent the data in a condensed yet comprehensive way. It would be most accurate to say that I used qualitative description with overtones of phenomenology to present a comprehensive summary of the daily living of these adolescent girls with epilepsy (Sandelowski, 2000).

Those who use qualitative description as a research method do not usually use a theoretical base or framework to guide inquiry or shape the structure and language of data analysis (Sandelowski, 2000). Research methods that fall under the umbrella of postpositivist, naturalistic inquiry will acknowledge some level of data interpretation because the researcher decides what questions to ask, the participant constructs his or her answer, and then the researcher makes subjective decisions about what parts of the data will receive attention during analysis and write-up. What makes qualitative description different from other types of naturalistic inquiry approaches is the effort to keep interpretation to this necessary minimum. I acknowledge that some data interpretation was necessary in order to present the findings in a meaningful and useful way, instead of as a list of quotations. However, I tried to avoid high level interpretation

and abstraction. Stigma theory may have influenced, but certainly did not guide my data analysis. My aim was not to “parcel out chunks” of narrative data into pre-existing concepts or categories developed from stigma theory. Instead, I hoped to stay close to the words of the participants while using elements of phenomenology to construct a meaningful summary of the events in the everyday language of the participants (Sandelowski, 2000).

The present research provides a rich and detailed description of the everyday lives of adolescent girls with epilepsy. I used first-level interpretation to group narratives into meaningful categories that would help readers make sense of the large amount of narrative data. While grouping narratives into categories, I tried to use the words of the participants to provide a summary of their narratives. I tried to preserve the voices of the adolescent participants, and summarize their stories in their own words (Guba, & Lincoln, 2005).

Methods

Participants

I submitted a research proposal to the Indiana University Institutional Review Board, which approved this research. To be eligible for the study, participants had to be young women aged 13 to 18 with a diagnosis of epilepsy and taking at least one seizure medication. Epilepsy is a heterogeneous disease, but for the purpose of this research study it did not matter what type of seizures the young woman was experiencing. Inclusion and exclusion criteria based on specific epilepsy diagnosis were not helpful for this particular research study. Instead, I thought that by comparing and contrasting the stories of the

participants who might have similar or dissimilar experiences, I might be able to uncover some important themes previously unknown (Charmaz, 2000, 2003). Some of the young women shared their exact diagnosis, while others talked about their symptoms, therefore providing clues about what type of seizure they had. Two of the young women had more than one type of seizure.

I used convenience sampling to enroll participants into the study. Potential participants were contacted by the leaders of two epilepsy support groups— one based in a large Midwestern city, the other in a medium sized Midwestern city. Participants (and their parents or guardians if under age 18) were given flyers (see Appendix A) about the study and asked to call me if interested in participating. Four potential participants were identified, and all voiced interest in the study. Despite her verbal interest and initial phone call to me, I was unable to schedule an interview with one of the young women because she and her parents did not return my phone calls to schedule the first interview. For the other young women, I talked with participants and their parents about the study and if they remained interested, I set up an interview at the time and place of their convenience. A fourth participant was identified through a social conversation rather than through the support group. I sent a flyer to the participant's mother who contacted me because her daughter was interested in the study. All participants were minors, so a parent or guardian signed a consent form, while the participant herself signed an assent form. Please see Appendix B. Participants received a thirty dollar gift card for participation in the study.

Data Collection

I conducted face-to-face, minimally structured, open-ended interviews with four adolescent girls with epilepsy. Please see Appendix C for a list of potential conversational openers used in the interviews. In my research proposal, I estimated that I would interview up to 10 participants. The number of participants in a qualitative description is less important than the quality and comprehensiveness of the narrative data. Creswell (2007) found “many examples” of narrative research with one or two participants (p. 126). Swenson (1996) calls for selection of respondents to occur “*serially and contingently*” to fill in gaps of understanding as patterns in the data are uncovered and constructed into a meaningful presentation by the researcher (p. 189). In this research, data collection and analysis occurred simultaneously. After conducting seven interviews and analyzing the text from these conversations, I realized that I had enough narrative data to create a meaningful summary of what it is like to live as an adolescent girl with epilepsy. I finished three more interviews after this point and included these narratives in my analysis. For this research, I did not conduct an exhaustive investigation of what daily living was like for every adolescent girl with epilepsy in the United States. Instead, I stopped enrolling participants when I saw patterns and repeating threads of stories that could be woven together in a way that told a larger story of what it was like to live as an adolescent girl with epilepsy.

My proposed timeline of interviews also served more as an estimated schedule that was influenced by the reality of busy lives. I proposed that I would

interview each adolescent girl three times: at baseline, 1 month, and 2 months after enrollment into the study. It was difficult to follow this exact timeline. The first participant's interviews took place at baseline, one month later, and then about six months later. I interviewed the second participant only two times about one month apart. I telephoned her repeatedly to schedule the third conversation, but neither she nor her parents returned the call. I noticed that their family business in the city in which she lived had closed, so I am not sure if she moved or decided not to do the third interview. I was able to interview the third participant according to the proposed timeline. The fourth participant had a demanding school schedule and was able to complete two interviews.

The purpose of conducting multiple interviews was twofold; first, to build a relationship with the participants so they felt more comfortable talking about potentially sensitive topics, and secondly, so that they had time to reflect on previous interviews and include new narratives or stories that came to mind. My original intention was to use only open-ended interviewing techniques, giving broad, non-directional prompts and letting the participants talk about what was most important to them at that time. With the first two participants, I began the initial interview by asking them to tell me about a typical day in their life. Both young women responded with a list of when they woke up, what they ate for breakfast, what time school started, and so forth. I learned that the adolescents needed assistance from me to find their narrative voice and talk about issues instead of schedules. My interview approach changed from open-ended to semi-structured. I began to ask more pointed questions, such as, "Tell me about a time

when it really seemed to matter that you have epilepsy". Please see Appendix C for other conversational openers. I noticed that the young women had a lot to tell me during the first and second interviews, but were repeating stories and concerns in the third interview. The first and second interviews typically lasted about ninety minutes. The third interview with each young woman was short, lasting about thirty minutes. It felt like they had told me what they wanted about living everyday with epilepsy and had little more to add. All interviews were audio-taped and transcribed verbatim. I also took field notes during the interviews to capture my own feelings and thoughts and the nonverbal behaviors of myself and the participants. At the end of the final interview, participants also completed a short 8-item scale that measures perceptions of stigma (Austin et al., 2004). Please see Appendix D for the Child Stigma Scale and Appendix E for a summary of scores. Because I was unable to conduct a third interview with the second participant, she did not complete this scale. The timing of the administration of this scale was intentional to prevent sensitizing the participants to the idea of stigma.

Data Analysis

I began to analyze the narrative data as soon as I transcribed the first interview. I continued data collection and analysis simultaneously as the research project progressed. The purpose of this project was to describe the everyday experiences of adolescent girls with epilepsy. The framework and context of the analysis was naturalistic inquiry and qualitative description. The end product is a comprehensive description in the words of the participants of what it is like to live

as an adolescent girl with epilepsy (Sandelowski, 2000). I stayed close to the words of the participants and tried to group similar thoughts, notions, and patterns with a minimum of abstraction. My analysis used overtones of phenomenology (van Manen, 1997). My analysis is situated within the context stigma theory as well as theories of adolescent development. I acknowledge that my thinking was influenced by these theories, however; I attempted to keep interpretations of the words of the young women to a minimum.

I did not follow a formulaic of data analysis, such as grounded theory method or narrative analysis. I also did not use interpretive phenomenology. However, my method of data analysis was influenced by van Manen (2006) who wrote, "Although method (in the usual sense of following directions, procedures, or orientations) can, indeed, give guidance, one cannot rely on it" (p. 719). Instead of following a prescribed method of data analysis, van Manen (2006) calls for the researcher to be sensitive, creative, and intimately involved with the text of interest. Janesick (2000) has written that data analysis can be rigorous, yet open-ended and flexible according to the nature of the text. My analysis of the data was not piece-meal or disorganized, but I cannot say that it followed in totality any prescribed method. My analysis of the data was careful, thoughtful, and reflective. I will now write a precise step-by-step description of how I analyzed the data. My intention here is for the reader to have a clear view of what I did to come to my constructed conclusions.

In my research proposal, I stated that I would transcribe each interview verbatim. I had intended to be the only transcriber. However, as this task became

more and more time consuming, I arranged for a professional transcriber to help me. All interviews were transcribed verbatim. I then listened to the audio-recordings while simultaneously reading the text. I then took out my field notes from that interview and reviewed them. Next, I read the text carefully, line-by-line, and highlighted text that expressed one idea or complete thought. This type of data analysis has been used in grounded theory studies to make sense of large amounts of narrative text (Charmaz, 2003; Lincoln, & Guba, 1985). At this time, I did not label these units of text, which have been called “meaning units” (Charmaz, 2003; Lincoln, & Guba, 1985).

Using Microsoft Word™, I split each transcript into two columns. The text was on the left. On the right, I was able to use a function of Microsoft Word called a “sticky note.” I would read the highlighted portion of text on the left, and summarize what I thought that meaning unit was about in a red sticky note on the right. My summaries were not abstract. Instead, I tried to use as many exact words from the participant as I could. I tried not to interpret these meaning units, or label them in an abstract way.

This preliminary analysis of the text was helpful as I would go to conduct another interview. These preliminary meaning units raised other questions or issues in my mind that I wanted to clarify with the next interview. This preliminary analysis helped me to flesh out beginning ideas or stay attentive for conflicting stories.

Once I had sticky note meaning units on the right side of the transcripts, I printed them out. I then read the sticky notes and placed them in piles according

to stories or notions that seemed similar. By placing the sticky note summaries into piles, I was trying to recognize and construct themes that seemed important in the everyday living as an adolescent girl with epilepsy. This step of the analysis was influenced by phenomenology. Although I was not trying to distill the words of the young women down to a phenomenologic essence, I did use some interpretation to sort and organize their thoughts and stories into meaningful thematic summaries. I did not want the thematic summaries to become too abstract, as this is not what is desired in a straightforward qualitative description. I tried to use the actual words of the participants to name the thematic summaries. In doing so, I hoped to stay true to the voices of the young women, and re-present in their words what it is like to live everyday as an adolescent girl with epilepsy.

It was helpful that data collection occurred simultaneously with analysis, as I was able to use subsequent conversations with participants to explore or clarify themes that were developing. I was able to share some preliminary findings with participants, and ask if these themes rang true. Some participants agreed with developing themes, while some provided narratives that contradicted what I had initially thought. This increased my breadth of understanding of each theme, hopefully allowing for a fuller, richer, more comprehensive description. The simultaneous data collection and analysis helped me to decide when sampling of participants could come to a close and themes became well-described.

I also evaluated quantitative data from the Child Stigma Scale (Austin et al., 2004). I compared individual scores on the scale to the narrative words of each participant to see if their stories and scores seemed consistent. This technique is not meant to confirm or refute that these adolescents do or do not perceive stigma in their everyday lives. Rather, the administration of this short instrument was simply another way to gather additional data to help better understand the experiences of these young women.

To complete the qualitative description, I represented the constructed themes to provide a detailed, thorough summary of what it is like to live everyday as an adolescent girl with epilepsy (Sandelowski, 2000). The method detailed above was used to generate a minimally interpreted, qualitative description of the everyday experiences of adolescent girls with epilepsy.

Quality Criteria

In this type of qualitative research, it is neither expected nor helpful for me to try to assure readers that my construction of the everyday living of adolescents with epilepsy is the one true representation of their story. Indeed, another researcher who interviewed the same young women might have chosen to ask different questions or group narratives in another way. Instead, as the researcher and writer of this narrative, it is my burden to show readers how my study maintains rigor, authenticity, and trustworthiness. It is my responsibility to make sure that my findings are in some way useful and that I ultimately feel confident that the findings could be used by others for future research or guidance with social policy (Guba, & Lincoln, 2005). Ultimately, I think that the most important

step in demonstrating this study's trustworthiness and authenticity is providing a transparent, detailed description of exactly how I collected, handled, labeled, grouped, and represented the data. If a reader can follow what I did, he or she can decide if they agree or disagree with my constructions and findings.

Specifically, I engaged the strategies of descriptive validity and interpretive validity (Maxwell, as cited in Sandelowski, 2000). In this paper, descriptive validity refers to an accurate account of events, while interpretive validity refers to an accurate representation of the meaning of the participants words (Sandelowski, 2000). These quality criteria are similar to the criteria of confirmability and credibility (Lincoln, & Guba, 1985). Confirmability is the notion that the researcher has been careful to ensure the accurate collection of data, and can trace the data back to the participant who provided it. Confirmability, or descriptive validity, may be demonstrated by tape recording participants' words and transcribing them verbatim. Confirmability may also be demonstrated by using verbatim quotations from participants when writing up the research report. I used both of these strategies in this research. Credibility is ensuring that there is agreement between a participant's perception of meaning and the meaning that is constructed by the researcher. When developing the description of everyday living of adolescent girls with epilepsy, I used the words of the participants when labeling meaning units of data and even when developing thematic categories. In staying close to the words of the young women, I believe that I fulfilled the criteria of credibility.

Descriptive and interpretive validity, as well as confirmability and credibility are crucial to ensuring rigor in a qualitative description. In this type of work, the researcher is attempting to construct a minimally interpreted description. It is therefore easy to recognize that in order for the description to be meaningful and useful, the researcher must try to accurately preserve what the participants said, as well as what they meant.

Dependability is another quality criterion that is important in a qualitative description (Guba, & Lincoln, 1982). Dependability is the notion that data collected during research should remain stable over time. That is, the researcher should be able to account for exactly what happened to the data. For example, she should keep a meticulous record of how data were broken down into units, how it was grouped, and how it was represented in the research report. I think that my previous description of methods used in this research demonstrate dependability of data. I described how I split each page of transcript into two columns and used sticky notes on the right to label meaning units of data. The labels of the meaning units were not abstract interpretations, but rather the exact words of the participants. These coded transcripts are saved and available to any reader who would wish to audit them. I then placed meaning units that seemed to be about similar notions into piles, and developed these notions into working themes. I have a list of working themes and the meaning units that were in that group and that is also available for any interested reader.

More recently developed quality criteria have been described in relation to interpretive research (Guba, & Lincoln, 2005; Lincoln, 1995). These quality

criteria are relational, in that they stress the intimate relationship between the researcher and participant. Positionality is the notion that there is no one truth about a phenomenon that is waiting to be discovered by a researcher (Lincoln, 1995). Instead, the researcher's culture, background, historical time period, race, gender, and previous education and knowledge will influence the questions that she asks, the data that she collects, and the way in which she interprets and analyzes data. In this way, the knowledge gathered through a research question is subjective and interpretive. Although the goal of qualitative description is to keep interpretation to a necessary minimum, it is crucial for the researcher to recognize positionality so that she does not make claims that her research has found the one and only truth of the matter.

Guba and Lincoln (2005) discuss reflexivity as important in qualitative research. They call the qualitative researcher to reflect "critically on the self as researcher" (Guba & Lincoln, 2005, p. 210). This intense reflection should include thinking about who I am, what I already know, what I believe, and what other things in life are important to me and constrain my time on this project. Positionality and reflexivity have helped me to realize several things about this project. First, I have knowledge of adolescent development and stigma theory and my findings will most likely be situated within the framework of these theories. Secondly, and honestly, I would have liked to have more time to work on this project. As a working mother of two small children, I often felt pressured and rushed to get portions of this dissertation finished. I would have liked to create a more beautiful piece of writing, represented in a more artful way.

However, the description of the everyday living of adolescent girls with epilepsy is authentic in respect to their own words and represented in a straightforward yet comprehensive manner.

An important way in which I tried to maintain authenticity and trustworthiness in this study was by paying close attention to voice (Guba, & Lincoln, 2005). I used the exact words of the participants to code meaning units. When labeling themes from groups of meaning units, I tried to stay as close to the words of the young women as possible. I used quotations throughout the write-up of this description. I kept the flavor of adolescent language intact by not removing any fillers from the quotations. For example, if a young woman said “like” five times within the sentence, I kept the word there even though it did not add meaningful content. I think my careful attention to voice makes this research authentic and I think I stayed true to the words of the young women. I think that my representation of what the young women told me is accurate, rigorous, and will be helpful to other researchers and nurses who care for adolescent girls with epilepsy.

CHAPTER 4

FINDINGS AND DISCUSSION

The following is a summary description of the everyday living of United States adolescent girls with epilepsy. For this study, I did not aim to use interpretive phenomenology to create conceptual themes from the data. Instead, I wanted to stay close to the words of the participants and describe what it is like to live everyday as an adolescent girl with epilepsy. However, listing quotations from the young women would have been unwieldy and disorganized, and probably would have made little sense to any reader. Therefore, I used qualitative descriptive methods with overtones of phenomenology to group the everyday experiences of these young women into themes that organized and made sense of their stories. The themes are not abstract, but rather organized summaries of stories and thoughts that seemed to belong together. First, I will present themes in which the participants described their everyday living as being similar to any other adolescent or dealing with important issues besides epilepsy. Then, I will transition to themes in which having seizures was a central focus to the everyday living of these young women.

Some of the stories and direct quotations in this chapter are intensely personal and detailed. In order to protect the identities of the participants, I have given each participant a pseudonym. Other details regarding the schools that they attended or names of friends and family have also been changed. Please refer to Appendix F for fictitious descriptions of all participants. I have created

these profiles as a way for the reader to develop a mental picture of the participants.

I Am Like Everyone Else (Except for my Seizures)

In the present study, the adolescents described lives that were similar to many other adolescents. Common activities for the participants included being with friends, going to the mall, going to the movies, eating pizza, and going to birthday parties. They talked on cellular phones, used text messaging, used computers for school work and down-time activities, and downloaded music to their digital music players.

The young women in this research study recognized that their seizures were a phenomenon that most others did not have, and in this respect they felt “different”. However, two of the participants clearly articulated that every person has something that makes them “different”, such as a health condition, a living situation, or social label. In this respect, the participants felt like any other teenager.

When I asked one participant, Brianne, what she called her condition; she rejected the idea of a label, saying,

I don't really label it myself either....It's just, like, you're labeling preps and nerds and jocks like that, and it's like you're labeling people with different sicknesses. I don't see what the difference is....It just bugs me because, like, I know people who actually do have 'em [seizures] and I have 'em and, like, they're perfectly fine too. Like, there's nothing different about them except for that.

Another participant Katie accepted her seizures as something that made her different from other teenagers, but in her mind, “everybody's messed up somehow one way or another,” so in this respect she was just like everyone else.

She eloquently said, “And I mean I do care because I know it’s like a misfiring, and it’s not supposed to happen, but then again nobody’s perfect.” McEwan, Espie, Metcalf, Brodie et al. (2004) reported similar findings from their study of Scottish adolescents with epilepsy. These researchers constructed a Sub-Theme titled “Epilepsy as Part of Me” in which some adolescents viewed their epilepsy as simply another characteristic of being an individual, such as personality or appearance, and not necessarily something that would separate them as being different (McEwan, Espie, Metcalf, Brodie et al., 2004, p. 22). Though McEwan, Espie, Metcalf, Brodie et al. (2004) asked their focus group participants about people and places important in their daily lives, their article did not include quotations about mundane aspects of living day-to-day as an adolescent with epilepsy. It would be interesting to read the raw data to see if the adolescents talked about common experiences of adolescents, such as eating out with friends and going to the movies.

The young women talked about feeling like any other adolescent, and that seizures neither influenced their lives nor stopped them from doing what they would like to do. One participant said that epilepsy, “is just not stopping me from doing anything.” Just like any other teenager, both Brianne and Rebecca were able to attain the milestone of achieving a driving license despite having seizures. Brianne said, “Whenever I went to get my permit we gave them the little note and that’s about it.” Some people with epilepsy are restricted from driving due to active seizures. As the two participants of driving age, Brianne and Rebecca had managed to remain seizure free for enough time to get their

learner's permit, and eventually their driving license. They talked about this step as important in feeling like a regular teenager.

Rebecca's story provides another example of how these young women did not define themselves by their medical condition. Rebecca had her first seizure at about age 13. At this time, her medical diagnosis was "seizure disorder." She then described having a second seizure which changed her diagnosis to "epilepsy." I asked her if the change in medical diagnosis from seizure disorder to epilepsy caused any changes in her image of herself. She was quick to reply, "No. Not really. Because epilepsy is something that I can't help." She continued to tell me that her identity was much more about being an excellent musician and student. She was an honor student, but more importantly to her, an excellent flute player and the section leader in her marching band. Her goal in life is to become a music professor at a university. Because heat triggers her seizures, she tended to have several seizures during summer marching band practices. I asked her if she ever considered *not* participating in marching band. She replied, "Marching band is something that I enjoy. I'd never let my seizures get in the way of that."

Rebecca had constructed a self-identity largely composed of being a musician. Her seizures did not define her. Developing key aspects of self-identity is a task of adolescence, and having a chronic illness can influence this process (Kennedy, Sloman, Douglass, & Sawyer, 2007; Simpson, 2001). Other research on adolescents with epilepsy has highlighted the importance of the development of a strong and stable self-identity on quality of life (McEwan Espie, Metcalf,

Brodie et al., 2004). Identity formation theory proposes that self-identity is comprised of multiple representations of the self (Stryker, & Burke, 2000). In any given situation, one might choose to bring forth one identity over another. This is called social salience (Stryker, & Burke, 2000). Rebecca was realistic. She recognized her seizures and knew their triggers. But her identity was not solely about being a teenager with epilepsy. Instead, she chose to define herself as a musician— something that gave her enjoyment and fulfillment. Her “difference” as a talented musician was more central to her self-identity than her “difference” as a teenager with epilepsy.

Rebecca's central identity was a musician. She did not deny that she had epilepsy, but this identity was at the periphery of her consciousness. At one point during an interview, she told me that she really did not like taking her medication. I asked her to elaborate. She replied,

I don't like the *idea* of taking medication to make me normal. Some people just get up and go about their day. I think they take that for granted. I don't like the idea of depending on taking a medication.

For Rebecca, disliking her medication was not about side effects or interactions. Rather, taking her medication reminded her that she was dependent upon an outside source to prevent seizures.

There are Worse Things than Epilepsy

Two of the young women in this study described family situations, including death and divorce, which were much more upsetting to them than their diagnosis of epilepsy. When I asked the adolescent girls to talk about their daily living, I did not expect to hear so much about their family lives. Two of the participants were having significant difficulties with family relationships; mainly

due to not liking or not getting along with their mothers' boyfriends. These young women spent a large portion of at least one interview talking about how unhappy they were with the men that their mothers had chosen to date.

Brianne told me that her biological father was "worthless," but that her step-father had raised her as his own and become a father to her. An aspiring chef, she said, "He was, like, here for me the whole time. He's, like, the one who taught me how to cook and everything...that's, like, a reason why I wanna be a cook." Unfortunately, Brianne's step-father died of cancer about a year prior to my first interview with her. His death was devastating to Brianne. Adding to her distress was the fact that his biological daughter from a previous marriage was chosen to receive mementos of him, including a guitar and a necklace that Brianne had wanted as a keep-sake. The two families fought over his personal effects and his will.

Adding to this already stressful situation, Brianne's mother began dating another man in a time-frame that Brianne thought was too soon after her step-father's death. She said,

'Cause I didn't expect for my mom to jump in, like, to a relationship that quick after my step-dad died. And it's just kind of weird. 'Cause, like, I think every family would just want that time together, after somebody would've died....I think me and my mom and my brother could use some time together.

Brianne felt close to her mother. She said, "I'd do anything for her 'cause she's, like, awesome and everything...she's really important to me." Brianne felt that the presence of the new boyfriend prevented her from being as close to her mother as she wanted, and prevented the family from grieving the loss of their step-father and husband. She said,

It's just, like, sometimes...I don't know...sometimes things get in the way...I'll be, like, talking to my mom or whatever and, like, Toby [not his real name] will start doing something [else] and I'll try to do something with my mom...it's just, like, we don't sit down and do much together anymore because of Toby.

Brianne told me that having her mother's new boyfriend around was stressful because she did not get along with him, and they often had fights. She did not think that this boyfriend respected her or her own boyfriend. The relationship between this man and Brianne's mother was unstable, and this was stressful too, as Brianne did not know what to expect. She said, "My mom will go through phases where she'll kick Toby out, want him back, kick him out, want him back, And, like, now, supposedly, he's out of the house."

On another occasion she said

She just has, like, times where she wants to get a different boyfriend and everything. Like, Friday night, she has, like, this really good guy friend, like, really good, and his wife passed away from lung cancer, and um, Friday night Toby was gone...and me, my mom, my boyfriend and my brother had dinner with her friend, and it was, like, really nice and everything...and, like,...she says that, like, Toby is Mr. Right Now and Charles [not his real name] is Mr. Right, but I was like, okay well, what're you gonna do?

Brianne's life has been disrupted by both divorce and death. Not knowing if her mother's relationship with her current boyfriend was permanent or temporary must also be incredibly stressful. In their summary of evidence on adjustment following divorce, Kelly and Emery (2003) report that re-partnering after divorce can be stressful for children, creating anger, role ambiguity, and family conflicts. These issues can be even more stressful when parents enter relationships soon after divorce (Kelly, & Emery, 2003). Skaggs and Jodl (1999) report that the

complex relationships found in some stepfamilies can place adolescents at risk for adjustment problems. Brianne's story certainly seems to mirror the findings in this research.

According to a synthesis of research on adolescents, one of the major tasks of this developmental stage is renegotiating relationships with parents and parental figures (Simpson, 2001). This is not a simple situation in which the adolescent severs ties with the parent and assumes responsibility for all decision making. This is a process of assertion of independence intertwined with periods of reconnection with parents. The teen-parent relationship can be influenced by the presence of a step-parent as well as by strain within any parental relationship (Simpson, 2001). Brianne's story seems to provide a vignette to illustrate the research. She wants to be close to her mother and reconnect. However, her mother's tumultuous relationship with Toby creates a barrier. She rejects Toby and in doing so rejects her mother's company as well.

Katie was the second participant who spent a good deal of interview time talking about how much she did not like her mother's boyfriend. Katie's parents divorced when she was in the third grade. She voiced a concern similar to that of Brianne when she said

But, I didn't expect my mom to move on so fast. Like, when I thought of her divorcing my dad, I thought of us, like, moving in a house together for a year or two by ourselves, just being us. Not her having Jeff (not his real name) there. Don't get me started. I cannot stand him. I hate his guts.

Katie did not mince words when it came to describing her mother's boyfriend, Jeff.

I told mom if she married Jeff I would move out and live with my dad. She laughed. I'm not kidding. I cannot stand him. He's a lazy bum, he has no job, he does nothing but sit there on...unemployment. And he sits there and he acts like he has the right to own the house and yell at us, and I'm like....I don't think so....and he's, like, you need to stop being such a brat...and I'll be, like, no thanks....I cannot stand him. At all. Me and my sister and brother cannot stand him. I do not like him one bit...mom...will not listen to us about Jeff. She's like thick-headed. Even her family doesn't like him. Her mom, her sister. They don't like him either. But she won't listen to us. I mean, why be with someone who just sits there on his lazy butt all day and does nothing? It's stupid and idiotic and all they do is sit there and fight too. And all he does is get drunk and they fight and it's just stupid. I remember one night they were sitting there fighting so badly.

Simpson (2001) encourages parents to model the type of healthy relationships that they would like for their adolescents. It was clear to Katie that her mother's current relationship with Jeff was unhealthy. This was having an emotional impact on Katie. The words of Katie and Brianne are a reminder to me that these young women were dealing with issues that were more upsetting than a diagnosis of epilepsy. The disruption within their families was much more at the forefront of their minds than their epilepsy. These young women were more upset about their troubled family relationships than they were about having seizures.

My Parents Trust Me

All of the young women in the research study talked about having to gain the trust of their parents as they became more independent. The participants wanted to go out with friends unsupervised by their parents. Many times they wanted to stay out with friends until midnight or even later. As they talked about going out with friends and having curfews, two separate issues emerged. The first issue was about gaining trust in a general way, similar to any other

adolescent as social plans changed, meeting places changed, and curfews stretched. Brianne said,

She doesn't really care as long as like, I'm in by my curfews. And if I'm gonna be late, then I always call her. Or if, like, I'm doing something and my plans change, I'll call her too. But like, I don't know, I think that makes her trust me a little bit more too.

The other issue was also about building trust, but alluded to safety issues.

With the exception of one situation which I will describe below, I am unclear whether the young women who talked about safety were referring to seizures specifically or general safety issues. In another study, I would clarify statements like this one from Marie: "My parents let me bike around the neighborhood by myself or whatever. I mean, they've, like, never worried. They know if something happens they know that I can take care of myself." I should have asked Marie about this statement, clarifying whether her parents knew she could take care of herself during a seizure or if she was talking about general safety like falling off the bike or getting lost. Katie also made a statement about safety saying, "As long as I'm okay and she knows I'll be safe and with someone she trusts, my mom lets me go out." In retrospect, she could have been alluding to seizure safety, but at the time I heard this as general safety for a thirteen year old adolescent girl out with friends.

Seventeen year-old Rebecca described how she and her parents dealt with the specific safety issue of being a teenage driver and a person with epilepsy. The law in Rebecca's state is that one must be seizure-free for ninety days in a row in order to maintain a driver's license. If a seizure

occurs, the person must relinquish the license until ninety days have passed with no further seizure activity. Rebecca's seizures are heralded by about fifteen minutes of a prodromal aura. She always becomes hungry and hot prior to a seizure. If she stops what she is doing, gets something to eat and cools down, the seizure is usually aborted. If she ignores the warning signs, then the seizure continues. Most of the time, she does not lose consciousness during her seizure activity.

Rebecca, her parents, and her neurologist have decided that in her case an aura does not represent a seizure unless it continues to involuntary muscular contractions. Therefore, if she has an aura, she must sit down and take care of herself to prevent a seizure. She can continue to maintain a driver's license as long as the aura does not progress. She has built a level of trust with her parents and her neurologist because she knows, understands, and successfully manages her chronic illness. She knows when she will have a seizure, and is adamant that if driving, she would have enough time to pull over and call for help. Even so, in another interview, Rebecca sighed, "My mom makes me call her every day when I get to school. I call her and say, Mom, I'm here. Ok. Have a good day. Bye." In order to continue driving, Rebecca is required to check in with her mother daily when she has arrived safely at school. Despite the visible annoyance on Rebecca's face as she told me this, it appeared that her family had worked through a potentially explosive situation and arrived at

a compromise that all could tolerate. Rebecca was allowed to drive as long as she took steps to decrease the worry felt by her mother.

Renegotiating relationships with parents is a developmental issue for adolescents with or without a chronic illness (Kennedy et al., 2007; Simpson, 2001). Teenagers need practice in making decisions for themselves and dealing with consequences that may arise. However, they need to do so in a controlled way, with parents awarding more freedom as teens show they can make responsible decisions (Simpson, 2001). In adolescents with a chronic illness, this transition to self-care can be more difficult as some young people with chronic illness have been sheltered by their parents (Kennedy et al., 2007). In this research, the young women report that their parents show flexibility with the rules as long as the girls act responsibly. The families in this research study seem to be doing well with navigating the transition from supervised young girl to independent young woman.

Am I Having a Seizure?

All of the young women talked about not always being sure if they were having seizure activity. Sometimes they could tell that they were about to have, or had already had a seizure. But at other times it was unclear. Brianne said,

I can tell when I'm going to get a seizure because I get really, really hot. It is usually when I'm asleep. I supposedly had one my freshman year at school. I got, like, really hot and I thought I was gonna throw up. But I don't know if I did or not. And then I was at the movies with [my boyfriend] and I don't know if I did or not.

Marie was also sometimes aware of her seizure activity and sometimes not. She said that she had seizures:

Mostly, like, whenever I'm tired or I get upset about something is whenever I mainly have them. But, I don't really have them a lot and I don't really know if I have 'em because I don't really even, like, feel 'em at all. I just, like, have, like, little jerks and everything.

This comment was interesting to me because during the course of all of the interviews, Marie had the most visible seizure activity. When I talked with her, I could see her face twitching and jerking, and sometimes she seemed to lose a word or lose her place mid-sentence during speaking. Katie's words echoed her peers, "Sometimes I can feel but just sometimes I don't even know I have them."

Rebecca was also unsure of certain bodily symptoms. She told me that she often had difficulty distinguishing if she was simply hungry, dizzy, tired, or actually having a seizure. Rebecca had a long prodrome prior to her seizures that included feeling hot and hungry. If she took care to alleviate these pre-seizure conditions, she could often thwart progression to a full seizure. If she did nothing to change her situation, it was possible, but not certain, that she would progress to having visible seizure activity. This complicated her decision about whether she was experiencing a seizure or not. Any time she was hungry she might wonder, was that the beginning of a seizure? Because she had to be seizure free for ninety days in order to keep her driving license, she told me that she tended to attribute bodily symptoms to plain hunger or fatigue, rather than admitting the possibility of a seizure.

Under-recognition of seizures may seem surprising, but this is a common phenomenon. Tatum et al. (2001) studied the records of 502 patients who had undergone ambulatory EEG recordings that included a push-button for the patients to record when they were experiencing a seizure. The authors found 47

instances in which seizure activity was recorded on the EEG. Out of these 47 electroclinical seizures, 18 were not marked by patients as feeling like they had a seizure. In other words, 38% of the seizure activity was not recognized by the patients (Tatum et al., 2001). Heo, Han, Lim, Kim, and Lee (2006) also found that a significant number of people with epilepsy are not aware of their complex-partial seizures.

Bullying

An unexpected and unfortunate finding in this research was that three of the four participants had experienced some type of bullying while at school. Bullying is defined as repeated behavior by someone with more power or strength that is meant to harm the victim (Espelage, & Swearer, 2003; Raskauskas, & Stoltz, 2007). For the participants in this study, sometimes the bullying took the form of physical violence and sometimes it was psychological tactics such as ignoring and excluding. Either way, the bullying was clearly upsetting to the young women in the study.

Bullying Because of Seizures

One participant, Marie, spent the majority of her conversations with me talking about how she had been bullied in school since the first grade. She attended a small school in which most students had been together in the same class since kindergarten. The fact that the students had been in the same class for years was important because in her mind, this caused the bullying to carry on from one year to the next. One of our conversations occurred during summer

vacation, and she told me that she worried about going back to school because, “kids are just going to start back up where they left off.”

Marie felt that the bullying and rejection from her peers probably started because she had visible seizures and this made her appear different from the other children in the class. She described to me how she and another student in the class were labeled and marked as different from the others.

There’s one boy...he has ADD and um, he sometimes he can be funny and then sometimes he can just be annoying, but the guys... and some of the girls make fun of him because he has ADD. And so we’re like the main two that get picked on. And so they kind of consider us the class nerds.

Rejection because of a difference that is labeled as undesirable by a group is classic stigmatization (Goffman, 1963; Link, & Phelan, 2001b). In Marie’s case, her seizures marked her as being different from the rest of the class. The class labeled those seizures as undesirable and rejected her because of it.

Marie was subjected to some heartbreaking physical violence while at school. These most certainly can be classified as instances of enacted stigma (Scambler, & Hopkins, 1986). She told me, “On April Food’s Day one time they went...I was wearing a white school shirt, and they went and they sprayed ketchup on it.” She was not safe in the hallways at her school.

These people, like, knock my books out of my hand for no reason at all they’ll just like come up behind me and kick my knee cap or make me fall or push my books out of my hand or something.

Marie experienced other overt forms of teasing and rejection. “I guess I had a seizure or something so then, like, every time I walked past him he always went like this [imitation of her seizure].” Compared to the other participants in this study, Marie was the one who had to cope with the most overt forms of rejection.

Although her seizures were the factor that initially prompted her classmates to label her as different, Marie insightfully concluded that the actual seizures were no longer an important reason why she was teased. She felt that it had simply become a habit for other kids to make fun of her. She reflected:

It's probably...between first and third grade...it was probably because of my seizures, but from like, halfway, like in the middle of third grade on up 'til now, it's just been a habit that they can't stop and they just think it's just this humongous joke and don't really even care. They don't even think I have feelings.

I think that Marie's statement highlights an important point about adolescent peer culture. The peer culture of adolescence is such that some young people are capable of engaging in bullying and rejecting behaviors because of any perceived difference— not just seizures or epilepsy. Adolescent groups demand conformity for members to “fit in.” Any perceived difference can be enough to keep a person as an outsider (Waldrup, Malcolm, & Jensen-Campbell, 2008). Initially, Marie was rejected because of her seizures. Now she is just rejected out of habit. At this point, she said, “It's mainly the guys. They just, like, treat me like I'm this little speck walking around the hallways during classes. I don't know why. I don't know what I ever did to them. But, they just, like, hate me.” Marie realized that the bullying was no longer about epilepsy or about her being different from her peers. It was now a “habit” allowed to continue by teachers and parents.

Marie summed this up when she said

My mom told me to ignore 'em and I tried and tried but they still kept picking and they wouldn't stop....and then I went to the teacher finally and then she said that it's just a stage that the guys go through and I was like, I don't really think this is a stage because it's been going on since first grade...and then they don't really do anything about it. And it's a Catholic school still, and they're like...this was like a bully free school year...and they didn't do

anything about it...and I talked to the principal about it. She didn't do anything about it either.

According to Coloroso (2003), ignoring and avoiding bullying is not an effective strategy. It teaches the victim to continue being a victim and teaches the bully that he or she can continue the behavior without consequence. In addition, when parents minimize their child's concerns about bullying with a phrase like "just ignore it", this harms the victim.

After the second interview with Marie, I stood outside near my car talking with her father. In my field notes, I wrote down that Marie's father was a Boy Scout Troop Leader. A member of his troop was the boy who was the main perpetrator of bullying towards Marie. Marie's father said that he knew that this boy was giving Marie "a hard time" and he felt like "shaking him" for being so mean. Marie's father was visibly upset as he told me this, but also felt that correcting the boy's behavior was not "his job" but rather should be left to the boy's parents.

Rebecca described schoolmates repeatedly turning lights on and off while at school because they thought it might provoke her to have a seizure. Although seemingly less harsh than what Marie experienced, this type of teasing meets the definition of bullying. Her response was generally to try to either ignore the offending student's behavior, or educate him or her about her seizures which were not triggered by flashing lights.

Bullying Because of Something Other than Seizures

This leads me to describe the experiences of Katie. During our first interview, Katie appeared happy, bubbly, and almost ebullient. She laughed a lot.

She was stylishly dressed in the type of brand-name jeans and sweatshirts that are popular with teenagers. She wore make-up, jewelry, and her hair was carefully styled. She described a close circle of friends that would never allow other people to make fun of her because of having seizures. She said, "My friends are like my family. They are protective of me. If you mess with one of us, you mess with all of us." She was detailed in her description of her friends' names, things they liked to do together, and what they looked like. She told me that several of her friends were coping with various health issues including asthma, ADD, diabetes, heart defects, and epilepsy. These differences were not viewed negatively by Katie or her friends, but rather as a common thread of "weirdness" that created a bond between them. She said, "We all have something wrong with us, but I guess that's what makes us so close. We're all pretty screwed up."

About a month later, when I returned to interview Katie for a second time, her relationship with that group of friends had changed completely. She described an argument between the friends, and told me that none of the girls in that group had spoken to her in about two weeks. They would not speak to her at school, and when she went to sit in her usual spot at their lunch table, all the girls picked up their food and moved, leaving her to sit alone. This exclusionary behavior, however, had nothing to do with Katie's seizures or epilepsy. None of the friends pointed to that as a reason, and none had used it as a way to make fun of or tease Katie. I asked Katie specifically if her friends used her seizures as

a way to bully her and she responded, "It hasn't been an issue." Instead, her former friends ignored her. She told me,

The second I got to school none of them talked to me. I was like fine then. I'm not talking to anybody until they talk to me. And I haven't said a single word to any of them unless I had to, like in class or something.

Katie's story is different from Marie's story in that the cause of her exclusion was not epilepsy. However, both stories exemplify an adolescent peer social culture that can be harsh, judgmental, and capable of using bullying tactics to exclude peers whom are deemed undesirable. Marie was subjected to physical violence and overt rejection. The bullying experienced by Katie was more subtle but equally damaging. Simmons (2002) would describe the tactics used against Katie as alternative aggression. Her social group ignored her and would no longer sit with her at lunch. Relationships and social status are especially important to adolescent girls (Simmons, 2002). Adolescent girls tend to use alternate aggression tactics like ignoring, glaring, or spreading rumors because they are aware that the destruction of a relationship or a social position is devastating to the victim. Rebecca described teenage girls as "piranhas." Adolescent girls also realize that this type of aggression typically is more difficult for adults to identify and punish. It is relatively easy for a teacher to spot the senior football player who is pushing the freshman into a locker. It is more difficult for a teacher to see the disapproving glare cast by a former friend to her victim. Even if the glare is seen, adults tend to ignore it because its intent is difficult to prove (Simmons, 2002).

As I've described, Katie was currently the victim of exclusion by her friends. She was upset by this and talked about the situation with her mother who told her "you were worse." In fact, Katie divulged to me that she had also been a perpetrator of bullying. She reflected

I realized what a crappy friend I really had been to her because I used to get angry a lot and yell at her even though she did nothing wrong because I would just get angry a lot. I guess if I owe anybody an apology it would be her for being such a crappy friend.

I do not know if it was her mother's simple yet powerful words or her current situation of being the excluded one, but Katie certainly had a drastic change of heart. She developed a personal "Be Nice Clause." She even posted her clause on her MySpace page (an Internet-based social networking site) that served as both a public apology and a reminder to herself. This personal manifesto included the following sentiments

I made this "be nice clause" where I have to be nicer because after I was friends with them I realized what a ginormously huge brat I had been to everybody. So I made a "be nice clause" where I couldn't talk about anybody behind their back. I had to be nice to everybody to their face even if I didn't want to be and I had to try and control my temper. And so far I've been decent. I will admit that I messed up once or twice but I've been pretty decent at it.

I'm sure that Katie wished for her former friends to have a similar change of heart and stop ignoring and excluding her.

Coping with Bullying

The young participants in this research study had tried different strategies to end the bullying they were experiencing. Different strategies to end the bullying had different levels of success. The least effective strategies for decreasing bullying behavior were ignoring it and emotionally reacting to it. Marie

described reacting emotionally to the bullying and then trying to ignore the behavior,

Whenever it was the younger grades, I used to like bawl my eyes out and then after a while I just knew, I just figured out in my head they're not going to think it's funny so just tough it out and deal with it and so I just kind of like floated along and try not to make it look like it bothers me but they still do it anyways.

Marie elaborated on how ineffective both strategies were in a story about when the children in her class were allowed to move their desks to any chosen spot in the classroom.

It was last year, actually, whenever we were, like, in class and...everybody, like, switched their desks around because he let us...and I, like, wanted to stay by myself. Like, over where I usually sat and then the guys came over. They were like, hey— why are you sitting over here by yourself? Are you, like, so upset or whatever? And then they were like, yeah...so you don't like it whenever we pick on you...since you don't like that we're going to keep doing it even more and they just kept saying that and saying that and then...I...just...like...melted.

Coloroso (2003) agrees that avoiding the bully and/or reacting emotionally are not effective coping strategies. These strategies keep the victim fearful, while the bully's behavior is rewarded. This combination worsens the situation.

For Marie, confronting the bullies was more effective for decreasing bullying, at least temporarily. Marie talked about confronting her bullies and trying to reason with them.

They just started making fun of me and they started doing what the other kid did. Like, going like that and twitching and stuff and then I would realize I don't see how you think this is funny and all. Just put yourself in my place. How would you feel if people did that to you? And they were just like, oh, okay, and then they just kind of walked away and then they didn't, like, bother me for the rest of the week or anything after that because they actually thought about it.

This type of confrontation is not always helpful (Coloroso, 2003). Providing information to bullies and helping them to understand the feelings of those who they are victimizing has been a strategy employed by schools to decrease bullying. Unfortunately, as experienced by Marie, this rational explanation of what it is like to be bullied is sometimes only temporarily successful, and many times completely unsuccessful. In fact, many bullies already know and understand that what they are doing is hurtful to the victim (Espelage, & Swearer, 2003; Jacobson, 2007). Coloroso (2003) suggests an assertive statement, followed by a quick exit from the situation. For example, "This is a dumb place to be; I'm out of here" conveys disapproval to the bully, while the quick exit keeps the victim safe (p. 133). This is an interesting suggestion, but may not always be feasible.

A second strategy that temporarily decreased bullying was engaging in an activity at which she excelled. Marie was victimized at school; however, she is a talented athlete and her bullies tended to leave her alone when she was engaging in sports. She told me,

Sports times is mainly whenever they don't bother me about it. They don't really make fun of me because they know that those are the kind of sports that I like to concentrate on, and they know that I like to do good in sports and everything...and they know that I have fun doing sports and then like after games...sometimes we would go like have a pizza party or like go to someone's house and...just like hang out for a while or do something...and they would invite me then, but then the next day at school, it'd just start all over again.

If Marie was playing basketball or track and helping her team to win, her peers gave her a temporary reprieve from being teased. But this was short-lived. Once the event was over, the teasing and bullying resumed.

Some of the young women in this study reached out to friends for help with bullying and teasing. For Katie, this was effective, "My friends are like my family. They are protective of me. If you mess with one of us, you mess with all of us." Having at least one good friend is a protective factor against being the target for a bully (Coloroso, 2003). For Marie, relying on her peers for help with bullying was sometimes helpful and sometimes not.

Sometimes they try to stop it, but then sometimes they just stand right with it...and they don't want to get made fun of...made fun of themselves because of their sticking up for me...so they mostly hang out with people that make fun of me.

Indeed, bullying is about status and power and some are motivated to bully in order to preserve their own status in the social hierarchy (Jacobson, 2007). Nurturing friendships and teaching children how to reach out to others can be an effective strategy to protect a young person from being bullied (Coloroso, 2003).

Marie did not want her parents to intervene on her behalf, saying, "My dad tries to step in...and he just embarrasses me," but she would have liked teachers at school to set rules to decrease bullying. Marie thought that teachers and school administrators should be responsible to ensure a "bully-free" school environment. She did not think that the teachers or administrators at her school were doing their job. She said, "They don't want to do anything about it." Rebecca agreed that bullying continued at her school because teachers and administrators "did nothing," while the sheer size of her high school made surveillance of every situation impossible. Perhaps better teacher surveillance of behavior

and strict rules on bullying would have helped Marie's situation. However, in his summary of research on bullying, Jacobson (2007) noted that intense scrutiny of bullies while at school, coupled with discipline, was often not enough to decrease bullying behavior as bullies found subtle and almost undetectable ways to reject their victims.

The problem of school bullying is enormous and no one seems to have a formula that is successful in decreasing its presence in schools. Working with the victim to enhance coping skills seems to shift responsibility to the very person who should be relieved of the pressure of solving this problem. Yet, monitoring bullies and making them aware of how detrimental their behavior is does not seem to change their minds about bullying. Jacobson's (2007) transformational "change of heart" is probably what needs to occur for bullying to stop, but he does not provide concrete plans, just theorization.

Academic Difficulties

Three of the young women whom I interviewed described some type of academic difficulty. This is perhaps not surprising as it has been documented that children with epilepsy are at risk for academic difficulties (Austin, Huberty, Huster, & Dunn, 1998). Two of the participants were receiving a failing grade in at least one class. Brianne said, "I make pretty good grades. I only have an 'F' in one class and that's math, er Algebra. I don't like math...it's not hard, but....I don't understand it." Katie told me, "I'm making pretty good grades. I only have like one 'F'." Katie also told me that, "I do not like to read. I pretend that I'm reading and I daydream." Marie also struggled in school, "especially in math

class...I had trouble kind of learning everything...I was kind of slower than the rest of the class and I, like, couldn't really keep up.”

Despite their academic struggles, none of the young women were enrolled in any special education classes or received extra help beyond the traditional classroom. Fastenau, Shen, Dunn, and Austin (2008) found that 48.2% of children with epilepsy in their research study exceeded the strictest criteria for diagnosing a learning disability (LD). Using less stringent criteria, 56.1% of their sample met criterion for LD. Because of the high prevalence of LD in children with epilepsy, Fastenau et al. (2008) call for all children with this chronic illness to be screened for LD. All of the participants in this research study voiced concerns about their academic difficulties. Perhaps additional instruction or specialized tutoring may have helped these young women improve their academic performance.

In addition to problems with cognition, children with epilepsy may have difficulty paying attention. As Dunn and Austin (1999) described, these attention problems may be due to seizure activity, pharmacologic treatment, or co-morbid diagnosis of Attention Deficit Disorder. Freilinger et al. (2006) found that children who used multiple antiepileptic medications had more attention problems. Indeed, Katie talked about her tendency to daydream when she should be paying attention in class.

Missing school for doctors' appointments may also contribute to the girls falling behind in their classes. All of the participants mentioned that they had to

take time away from school, and sometimes multiple days in a row, in order to see specialists at a tertiary care facility.

Disclosure Management

Disclosure management is a group of strategies that people use to tell or not tell others about a potentially stigmatizing condition (Goffman, 1963; Jacoby, 1994). All of the participants in this study engaged in disclosure management strategies, and all wished that they had more control over who knew or found out about their diagnosis of epilepsy. All of the participants in the study wanted to be selective about whom they chose to tell about their diagnosis of epilepsy, but sometimes they did not have a choice. The young women had different reasons why they didn't want to tell others about their epilepsy, including not wanting other people to worry about them, not wanting others to judge them negatively, or not wanting to be picked on or bullied.

Marie was not open about having seizures. Because she had gone to school for years with the same classmates, she felt that she never had the opportunity to control whether or not she told others about her epilepsy. She said,

I didn't really wanna tell 'em, because I knew that once they figured out that I had something wrong with me they wouldn't want to hang out with me or anything. My class knew that I was a little slower than the rest of the class. And so they kind of figured out on their own.

Marie attempted to manage how often her disease was talked about by keeping discussion about her epilepsy to a minimum. She said,

I don't really like to talk to my friends and stuff about it because I don't really even like the fact that I have them. And I just, like,

wanna try and get rid of 'em and everything. So...I don't really like to talk about it much.

Like Marie, Brianne only told a few of her friends about her seizures. She said,

'Cause it hasn't, like, come up or anything and just cause...like, I don't know, like, I know I could trust 'em...but, like, I don't know if that, like, would be something I would actually tell. And I don't know if they would go around and tell everybody. And I don't know if they would look at me different either. And I don't want that.

Some of the other participants felt comfortable talking about their seizures to their close friends, but not Marie. She told me that she had two close friends, but, "They are the only ones I can trust...because they know that deep down it hurts me inside...I talk to them a little about it before...but not a lot."

The circumstances of Katie's diagnosis prevented her from keeping her seizures a secret. Katie is a social teenager, and spends a lot of time with friends. Many of her first undiagnosed seizures occurred in the presence of friends. She had symptoms at a church retreat with friends, and then again when walking home with friends. Her friends witnessed her seizures, and were therefore privy to the fact that she was seeking medical care. In general, Katie did not seem to mind that her friends knew that she was having seizures. After all, she was the young woman who felt that the different health problems of each of her friends brought the group closer together. Even so, she wishes that she had a little bit more privacy in regard to her medical condition.

Living with epilepsy, like, you have to go to the doctor a lot, which sucks because, like, you have to miss school and you have to go back the next day and explain to everybody. Like, everybody will be like— why were you gone? I'll be like— I was at the doctor.

Both Katie and Brianne thought that some, although not all, of their teachers needed to know about their epilepsy diagnosis. This wish is in direct opposition to some leaders in epilepsy research and education that advocate that all teachers of children with epilepsy need to know about an emergency plan for seizure activity while at school (Apel, & Hollingsworth, 2008). Brianne thought that her teachers should be notified that she had an unspecified health condition that may require her to leave the classroom at irregular and unpredictable times. She said, “An email should get sent out to my teachers that if I get hot and say I need to go, I need to go.” However, she had the concern that teachers might gossip about her because of her epilepsy. She said, “I mean as long as like the teachers don’t point me out and just like say— okay, yeah, she has that, let’s like talk about it or whatever.” It turns out that Brianne’s concern about teachers revealing personal health information to others is not unjustified. In Katie’s case, “I told my good friends, my mom told the school, and then a teacher with a big mouth said, ‘Don’t you have epilepsy?’ in front of the class.” It is hard to imagine a teacher revealing to the class other personal health information like having cancer or HIV infection.

Students with epilepsy and their parents should be able to disclose the diagnosis to teachers and school personnel with confidence that those entrusted to the information will not talk about it unnecessarily. However, if teachers cannot be trusted to protect this sensitive information, then I can understand why some students choose to keep their diagnosis secret from school personnel.

Three of the participants in this research study had boyfriends to whom they chose to disclose their diagnosis. For Katie, telling her boyfriend that she had seizures was not a problem and she did not hesitate. This seemed to be part of her larger attitude that, “we all have something wrong with us.” With a smile, she said, “I told the one I have now. Because he has ADHD and I’m like that’s okay.” She accepted his difference and assumed that he would accept hers too. It is possible that Katie felt so comfortable telling her boyfriend because at age 14, she knew that this was not going to be a serious, long-term relationship. In fact in the month between her first and second interviews, Katie had “dumped” one boyfriend because he moved away and was dating another young man. I asked her to think about the future and describe to me if she would always be so open in telling the young men she was dating about her epilepsy. She replied,

I don’t really know because, like, when you tell someone...the second they think it’s like...Oh my gosh...you’re gonna fall down. No I’m not. Or they start worrying and I just can’t stand when people worry about me because there’s really no need to worry. I’m not an idiot. I know what I can do and what I can’t and what I should do if I’m in that situation. I haven’t blacked out or anything yet, so they shouldn’t be that afraid of that. I’m still trying to get it under control, yeah but it doesn’t have to be as major as they make it sound. So I don’t know if I’ll tell them or not. I guess it all depends.

Katie’s concern seemed to be more about a boyfriend doubting her competence, and less about being rejected. I questioned Katie further, asking her how she would know if she could tell a new boyfriend. She described to me that in telling a new friend or boyfriend, she would have to be sure that the person was both loyal and trustworthy.

Seventeen year-old Brianne was in a more serious, long-term relationship with a boyfriend. He often stayed overnight in her bedroom and they were

sexually active. He has given her a “promise ring” which is not quite an engagement ring, but signifies a long-term relationship. Brianne struggled much more than Katie with her decision to tell her boyfriend, and perhaps this was because of the potential consequences on a more serious relationship. The reality that he could reject her must have weighed heavily on her mind. Joachim and Acorn’s (2000) concept of the visibility or invisibility of epilepsy is important in Brianne’s disclosure story. Her trigger to discuss her epilepsy with her boyfriend was his witnessing of a seizure. They were at a movie together and Brianne felt unwell, hot and sweaty. For Brianne, this pattern of getting hot usually precedes a seizure. Brianne described the situation at the movies: “He was like, are you okay, baby? I’m like— what? What? Like, I was hot and sweaty and everything and I was like— what? He was like— do you wanna go? I was like— no, I’m okay.” Her boyfriend started to talk to other friends about what had happened, and Brianne thought, “Okay, well I need to tell him now.” You can hear the anxiety in her words as she describes the night that she told him about her epilepsy,

I was going to have to tell him one way or another because, like, first of all I had one right in front of him so he was going, like, okay, well maybe she’s just a freak...so I thought it would be just best if I told him myself...I just told him that I had something to tell him. And we were in my room. And I just started crying so bad. And he said, no matter what it wasn’t gonna change anything so, like, I told him. And he said it wasn’t no big deal. So, like, it made me feel better.

Brianne expressed relief that she told her boyfriend about her seizures and his reaction was supportive. “I’m glad I told him because, like, I know that, like, I’m not hiding anything from him...and , like, he, he doesn’t hold it against me or anything. And, like, it just makes me feel better too.” In the previous quotation,

Brianne's boyfriend indicated that he would accept her regardless of what she was about to tell him. In her grounded theory study on managing disease-related information, Admi (1995) reported that people with cystic fibrosis selected their "audience" to tell about their illness based partially on whether those people used expressions of caring. Brianne's boyfriend expressed his devotion to her, and in doing so, became a trusted audience member whom she could tell about her chronic illness.

All of the participants were clear that they would not tell others about their epilepsy unless there was a clear and necessary reason to do so. An example of this sentiment is, "They don't need to know my personal business...and, like, if they did, if they really wanted to, then, like, they could, you know like, then they would be my friend if they, like, needed to know." Rebecca simplified this statement by saying that she told people on "a need to know basis."

A desire to be able to control information about epilepsy came out strongly on the quantitative Child Stigma Scale, which was administered as part of this research study. The scores of the participants mirrored their narratives. Three of the participants completed the scale. The fourth participant did not complete her third interview and therefore did not fill out the scale. Scores on most items were in the low to middle range (see Appendix E for summary data from the Scale). However, scores were higher on items seven and eight, both of which address disclosure management. Item seven asked "How often do you keep your seizure condition a secret from other kids?" Two of the young women responded with a 5, which was the highest number on the scale, and signified that they kept their

seizure condition a secret very often. The other young woman responded with a 3, which signified that she sometimes did this. Item eight asked the young women to consider, “How often do you try to avoid talking to other people about your seizure condition?” Two of the participants responded with a 3 (sometimes) and one responded with a 5 (very often). The young women in this study often kept their epilepsy a secret from other kids, and tried to avoid talking about it. This type of disclosure management is often used with stigmatizing illnesses. Westbrook et al. (1992) reported similar findings as the majority of the adolescents in their study kept their epilepsy a secret at least some of the time, and also tried to avoid talking about it.

Seizures are Scary to Have and to See

All of the participants talked about being scared of seizures when they first experienced them. The young women did not know what was happening and did not know what to expect from doctor visits. Katie and Brianne first experienced seizure activity in their teens. Katie told her mother, “I’m scared— Mom, you’re taking me to the doctor!” Brianne said, “I guess it was scary the first time ‘cause I didn’t know like what they were going to do to me or anything.” Marie had seizure activity at the young age of three and was also scared, “I was like crying because I was so young and didn’t even know what was going on.”

In their review of literature on stigma and epilepsy, Bandstra, Camfield, and Camfield (2008) report that the general population is fearful of people with epilepsy and fearful of people who are having a seizure. Indeed, seizure activity can look scary. The adolescent participants with whom I spoke were scared

when they saw others having seizures, even though they had experienced seizures themselves. Brianne had attended a camp for youngsters with seizures and it was the first time she witnessed a person having a seizure. She said,

It was kind of scary 'cause like I, like I know like what they're going through and everything, but like I've never seen somebody have one before, but like I can kind of like see it as like, like that's what I look like when I'm having one. It made me feel scared.

As I reflect on what Brianne is saying here, it occurs to me that I should have asked if she was scared for the individual having the seizure, or whether her fear was about how she herself looked or acted during a seizure. In retrospect, I would have liked to ask Brianne if it made things better or worse for her to have seen a person having a seizure.

If I Have a Seizure, Don't Attract Attention to Me!

All of the participants said that they did not want to attract attention during a seizure. The young women recognized that if they had a seizure at school or in another public place, they would need the help of a few key bystanders. They wanted the help of a few people, but did not want a crowd or audience. They also did not want others to talk about the seizure after it happened. All of the young women talked about this wish, but Brianne was the most vociferous and passionate about it. Brianne said,

In eighth grade, they didn't really pay attention to it, they just like kept everything going so they wouldn't pay attention, which made it better. But, like, my freshman year, they like stopped everything and made sure I didn't do anything...that made me mad!

She went on to say that:

[I wish kids would] act just like – kind of like nothing's wrong, but still, like one or two people....ask....if [I'm] ok. Cause like

everybody's asking...it just gets old. Cause like everybody doesn't need to get up in your business.

Rebecca also wanted people to "back off" during a seizure. Knowing how these young women would like to be treated during and after a seizure is important. Although some types of seizures such as generalized tonic-clonic seizures might be disruptive to the classroom, attention to other types of partial or absence seizures might be able to be minimized in a classroom or public setting. If one or two friends or teachers knew about the young woman's seizure type and what to expect during and after the seizure, those key support people could ensure the safety of the person with epilepsy, while helping the class to refocus attention away from the person having the seizure.

Silences

Charmaz (2005) writes that silences can be as important to the meaning of a story as that which is spoken. Being mindful to what participants *did not* say can raise questions in the mind of the researcher. Perhaps a perceived power difference or a lack of trust between researcher and participant caused the participant to hesitate to say something intensely personal. Perhaps the participant had yet to realize and make conscious something that was important to her daily living. In thinking about what I have read about adolescent development and adolescents with epilepsy; and in thinking about what it was like for me during my own adolescent years, I thought some silences in the interviews for this research were important to note.

In his synthesis of research on adolescent development, Simpson (2001) places adjusting to sexually maturing bodies and feelings as the number one

priority task for adolescents. Still, I was not surprised that that the young women did not really talk about physical intimacy with their boyfriends. Three of the young women had boyfriends, and the two oldest participants had dated their partners for at least a year. One participant's boyfriend spent the night in her bedroom on an almost daily basis. Yet, she was hesitant to answer when I asked if they were sexually active. Sexuality and sexual behavior is of course intensely personal. Finding out if seizures affected the participant's sexual lives, or affected the way in which they perceived their sexuality or sexual appeal would have been fascinating. However, I really did not expect these teens to open up to a thirty-five year old nurse over the span of three interviews and tell me these intensely personal things. It would probably take months of building trust and demonstrating a non-judgmental attitude for these stories to be shared.

I was, however, surprised that I did not hear concerns about being able to have healthy children in the future. Having seizures while pregnant can pose some, albeit minimal in most cases, risks to the developing fetus (Perucca, Beghi, Dulac, Shorvon, & Tomson, 2000). Anti-seizure medications can also pose some risks to a developing fetus (Perucca et al., 2000). I did ask about daily living, not future plans. However, all of the young women talked about plans for the future, including going to college and potential career choices. Perhaps the young women in this study were not aware that their chronic illness and its treatment had the potential to place a pregnancy at potentially higher risk. Perhaps they were aware of this potential problem, but the thought of having

children was more distant in their minds than going to college and choosing a career.

I heard very little about experimentation with alcohol or drugs. One participant had taken a sip of alcohol and did not like it. She also realized that alcohol might trigger seizures and so was not interested in experimenting with this substance. Again, revealing that they had experimented with alcohol or drugs may have been a topic that the teens felt was too personal to share. Perhaps if I had more time to build trust with the young women, they might have talked about this sensitive issue. But it is also possible that the young women were not involved with drugs or alcohol.

I also did not hear much about problems with anti-seizure medications. Each of the participants was taking at least one anti-seizure medication. Two of the young women mentioned in passing the type of seizure medication they took, basically describing it as a routine part of the day. Rebecca mentioned resenting her medication because she had to rely on it to be “normal.” However, none of the participants complained about side effects of their medication. Some anti-seizure medications have the potential to cause fatigue, hirsutism, acne, weight gain or loss, and gum hyperplasia (Perucca et al., 2000). Any of these side effects can be distressing to a person with epilepsy. None of the young women in this research had any side effects from their medication that were visually obvious to me. All of the young women were slender, but well-nourished with a healthy-looking musculature. None had acne, noticeable hirsutism, or gum

hyperplasia. Perhaps these young women took newer anti-seizure medications which tend to have less problematic side effects (Perucca et al., 2000).

Summary

In this chapter, I have written a thorough, vivid, detailed summary of what it is like to live every day as an adolescent girl with epilepsy. I grouped the narrative data into categories in order to represent the words of the participants in a meaningful and organized way. I did not try to move within and beyond the words of the participants to create an abstract representation of meaning, although I believe that the quality and richness of the data could accommodate this type of work. Instead, I tried to stay close to the actual words of the participants and tell their story of what it is like to live every day with epilepsy. A summary of the findings includes the following:

- The adolescent girls in this study described themselves as normal teenagers. They recognized that their peers did not have seizures, but felt that every person has characteristics that make him or her different from others.
- The adolescent girls chose social roles like musician or athlete to define themselves, rather than being a person with seizures.
- All of the young women were renegotiating relationships with parents, learning how to earn trust and be rewarded with more freedom and responsibility.
- The young women were often not sure if they were experiencing seizure activity.

- The young women thought that having a seizure and seeing another person's seizure was scary.
- If the young women had a seizure, they did not want others to attract attention to them.
- Three of the four young women were struggling academically.
- Complicated and serious family issues were more troublesome for the young women than their chronic illness.
- Three of the four young women had experienced bullying. Sometimes their seizures prompted the bullying. Sometimes the bullying had nothing to do with seizures.
- Having control over disclosure of their chronic illness was important to the young women. Most did not want teachers or acquaintances to know about their epilepsy. They wanted to tell those that they trusted in their own time and on their own terms.

These findings can be used to guide future nursing research, as well as policy and practice development.

CHAPTER 5

SUMMARY AND IMPLICATIONS FOR POLICY, RESEARCH, AND PRACTICE

This research study asked the question what is it like to live every day as an adolescent girl with epilepsy? I constructed a vivid description of the everyday living of the four young women who participated in this study. These young women were all living in a Midwestern state and were of Caucasian race. I do not expect their day-to-day experiences to mirror those of every adolescent girl with epilepsy in the United States.

Nevertheless, I would like my research to be useful to those who read it. I hope nursing and social science researchers find my description useful in helping to develop new research and intervention studies. I hope this research helps clinicians recognize the issues beyond a medical diagnosis with which a young woman with epilepsy may be coping. Teachers and school administrators who read this study may be able to develop better policies to deal with students with seizures, as well as policies that would help to protect private student health information. Perhaps young women with epilepsy and their parents will find comfort in some of these stories, or find new ways to think about and cope with this chronic illness. I will now summarize the findings from this research study and make suggestions for future research and nursing practice.

The young women in this study did not feel that they were fundamentally different from their peers, except for having seizures. They viewed the seizure activity as a minor difference from peers, similar to having another type of illness, or being labeled a “jock” or a “nerd” or a musician. This is an important finding

because their identities were not solely comprised of being a person with epilepsy. Research models of adolescent resilience include assets, or positive factors that reside within the individual, as being protective to the psychosocial health of teenagers (Fergus, & Zimmerman, 2005; Haase, 2004). In their research with adults with epilepsy, Goldstein, Holland, Soteriou, and Mellers (2005) showed that the way that people with epilepsy thought about their illness influenced their psychological well-being.

I think that a potential intervention to improve psychosocial outcomes for adolescent girls with epilepsy would be for clinicians to assist in helping them to identify and strengthen at least one asset. School nurses, therapists, nurse practitioners, or other clinicians could help these young women recognize something about themselves that was important, vibrant, and strong. This could include almost anything, including being an excellent musician, being a good friend, making good money at an after-school job, being a strong academic student, being an athlete, or having a hobby about which they were passionate. Clinicians could encourage these young women to think of their self-identity more in terms of their asset, and less in terms of being a person with epilepsy. In this way, a young woman becomes “that girl who loves to create sculptures” rather than “that girl with epilepsy.” In fact, this type of intervention could probably be used with almost all adolescents, whether chronically ill or not. Strengthening the assets of adolescents through the development of a positive, strong self-identity may help reduce the influence of risks on vulnerable teens (Fergus, & Zimmerman, 2005).

Some of the young women in the study talked more about their dissatisfaction with their family relationships than they did about seizures. This is an important finding because as researchers or clinicians, sometimes we have a narrow focus and preconceived ideas about what is important in the lives of those whom we are trying to help through our research or practice. This finding is a reminder that what we think is important to solve may not be a top priority to the person whom we are trying to help. Therefore, an open ended question may be a good tool to prompt discussion about what is most problematic in our patient's or participant's life.

Issues common to all adolescents were apparent in these research findings. Just like most other young women, the participants in this study were renegotiating relationships with parents in order to gain trust and assume more responsibility for their safety and well-being. This transition seemed to be occurring smoothly for all the young women in the study. A limitation of this study is that I failed to explore whether or not this transition was at all complicated by having a seizure condition.

It is common for people with epilepsy to under-recognize their seizure activity (Heo et al., 2006; Tatum et al., 2001). I still find it interesting that all of the participants in this study were sometimes unsure about whether they had a seizure or not. In this study, the under-recognition of seizures by the participants had several potential root causes. Perhaps a simple lack of attention made seizure recognition difficult. Perhaps some young women were embarrassed, and it was less stressful or hurtful to say they were dizzy rather than that they

had a seizure. Perhaps some under-recognition was more intentional so that driving privileges were not jeopardized. An interesting area of future research would be to try to uncover reasons (other than simple lack of awareness) why people do not report seizure activity.

Three of the four young women in this study were having academic difficulty. Children with epilepsy are at risk for problems with cognition, attention, and have high rates of learning disabilities (Austin et al., 1998; Dunn, & Austin, 1999; Fastenau et al., 2008). Seizures may have a negative effect on a developing brain (Berg et al., 2007; Holmes, 2001). Researchers are developing models of adolescent brain development and discovering how the adolescent brain is both anatomically and neurochemically different from that of the adult brain (Spear, 2000). A fascinating direction for future research with adolescents with epilepsy will be how the endocrine changes of puberty in conjunction with seizure activity affect the structure and function of the brain. A better understanding of the physiology of the neuroendocrine system and its effect on the adolescent brain in general and the adolescent brain with seizures specifically may help determine how to best help those with epilepsy and learning difficulties.

Elements of stigma were present in the lives of these young women with epilepsy. Stigma was apparent in how the young women used disclosure management techniques to tell or not tell others about their chronic illness. Although circumstances did not always allow the participants to control the information about their seizure disorder, all wished that they had the ultimate

power to keep their diagnosis a secret if they wished, or tell those whom they wanted. They tried to be careful about disclosure, telling only those people who were deemed trustworthy and loyal. They became upset if others made their diagnosis public without permission. They preferred only key people to know about their diagnosis. Similarly, they only wanted the help of key people during a seizure. Beyond the assistance of one to two people, the young women wanted everyone else to ignore them during a seizure and not call attention to it.

This finding is important in developing school policies about notifying teachers and support staff of children with epilepsy. There is a delicate balance between protecting the privacy of a student's health history, while simultaneously keeping that student safe. Brianne wanted only a few teachers at her school to know about her epilepsy. She wanted a generic memorandum to be sent to her teachers stating that if she felt she needed to leave the classroom, she should be granted permission. On the one hand, I agree with this point. Katie had the unfortunate experience of a teacher divulging her private health history to the entire class without permission. This would not have happened if only key people, rather than all her teachers, had known about her seizures. However, on the other hand, it seems risky to let a young woman with epilepsy out of the classroom unsupervised when she feels ill. If the teacher was not aware of the potential for seizures, the student may walk out into an isolated area like a restroom and have an un-witnessed seizure. Injuries after seizures are uncommon, but possible. Perhaps a better solution would be for school

administrators to engage their staff in workshops to remind them of the importance of protecting the private health information of their students.

The stigma of epilepsy was also apparent in the rejection, alienation, and physical violence carried out on Marie. I think the most surprising and disturbing finding from this descriptive study was the intensity and persistence of bullying and rejection of two of the young women by their peers. A third participant had experienced mild teasing which still could be classified as bullying. When I asked this participant specifically about bullying, she told me that she did not feel she had ever been a victim, but described teenage girls as “piranhas.”

As a nurse and a researcher interested in adolescents with epilepsy, I of course want to decrease the problem of stigma associated with epilepsy. However, through describing the everyday living of adolescent girls with epilepsy, it is apparent that this neurological disease was not the only reason that the girls were rejected. Just about any perceived difference can trigger the wrath of a bully. Focusing on interventions to educate teenagers about epilepsy may help those young women rejected because of their seizures. In fact, by conducting a 30-minute educational intervention about epilepsy, Martiniuk, Speechley, Secco, Campbell, and Donner (2007) were able to positively influence attitude toward epilepsy in fifth graders. But a neurological disease is only one of thousands of potential differences, and helping teens to accept those with seizures solves only a very small piece of the bullying problem.

To decrease and perhaps eradicate bullying, a comprehensive, coordinated approach that involves parents, school officials, and children is

necessary. Parents, educators, and nurses must get involved in these situations; however eradicating bullying behavior is a complicated endeavor (Espelage, & Swearer, 2003 Jacobson, 2007). Simply letting groups of adolescents know that their behavior is unacceptable is often not effective. Bullies usually know that their behavior is hurtful to their victim (Jacobson, 2007). Nevertheless, it is shameful that some American adolescents engage in culturally accepted bullying and victimization. Nansel et al. (2001) reported that in their study of over 15,000 adolescents in the United States, 13.0% identified themselves as bullies. The stories of my participants reveal that any number of differences can prompt bullying or exclusion. Any intervention to decrease the stigma associated with epilepsy or to increase acceptance of differences must be targeted at the group that is discriminating, rather than the victim (Link, & Phelan, 2001a).

A very simple but effective intervention is for parents to legitimize the feelings of their child by listening to their children's stories and concerns in a nonjudgmental way (Coloroso, 2003). The simple act of acknowledging the feelings of a child often helps to heal the wounds of teasing. Parents may feel like they need to "do something" to stop the bullying, and may not recognize that active, engaged listening is one of the best interventions to help heal and strengthen the self-esteem of their child.

Active, engaged listening to a child is more helpful than parents trying to solve the bullying situation for the child. It is usually not effective for a victim's parent to try to solve the situation or confront the bully and his or her parents alone (Coloroso, 2003). However, it *is* important for parents of the victim to

become involved. Parents may be able to teach their child how to respond in an assertive, rather than either passive or aggressive way. Parents can listen carefully to their child's fears and stories. Parents can also contact the school and develop networks with other parents to bring the bullying out into the open for the community to see and correct.

Jacobson (2007) summarized three major strategies that have been used to decrease bullying in schools. First, informing bullies that their behavior is hurtful is important, but most bullies already know this and reinforcing it does not seem to motivate any change in behavior.

A second strategy is to teach the victim skills to cope with bullying such as decreasing passive behavior and standing up for oneself. Coloroso (2003) suggests specific, assertive one line responses that convey disapproval without aggression. For example, she suggests a person who is being bullied could say something like, "This is beneath both of us. I'm out of here." (Coloroso, 2003). She also suggests encouraging children to engage in behaviors that protect against bullying, like being friendly, open, and willing to join in a group.

Thirdly, increasing school surveillance of bullying has been incorporated into plans that hope to decrease this victimization. As Jacobson (2007) eloquently narrates through his story of Matthew, sometimes even the best combination of these three strategies does not work to decrease bullying. Jacobson (2007) calls for a "fundamental change of heart" for bullies (p. 1933). This change can only come about when the culture of adolescence is changed. The culture of adolescence cannot change until the culture of the United States

changes. Instead of rewarding competitiveness, we should reward connectedness (Jacobson, 2007). Success should be measured by how much we help one another achieve, rather than how high we can rise compared to our peers. Differences should be celebrated and valued. This idea is complicated and involves a seismic shift in the way people in the United States think. This idea may seem too broad or too challenging, or even unappealing or anti-American; but the psychosocial well-being of so many of our youth is at stake.

I will now summarize implications of this research for future policy, research, and practice.

Implications for Policy

- Each year, children and adolescents with epilepsy should be screened for learning disabilities and attention disorders, and should receive supplemental instruction as required.
- School nurses should develop modules for administrators, teachers, and school staff on protecting student health information. This could be a short, yearly training seminar on what type of health information is protected, and how current law prohibits information being shared with those who are not essential in the health care of the student. Administrators should work with parents and students with chronic health issues to develop individualized, written plans to decide if key personnel within the school need access to that student's private health information for the well being of the student.

Health information about the student should only be shared with those essential personnel.

- School administrators need a comprehensive policy regarding bullying. Students should be able to report bullying without fear. They should be able to report anonymously to teachers and administrators instances of bullying. There should be a no-tolerance policy for bullying. Any bullying behaviors should be met with strict and swift punishment to convey the message that it will not be tolerated. All remote areas of a school, including bathrooms, gymnasiums, and cafeterias should be strictly monitored either with the presence of teachers and staff, or video-surveillance. Most importantly, school officials need to develop a curriculum that teaches tolerance of differences, caring for one's peers, and strengthening of individual self-esteem. Teachers could take an hour each week to let students talk about things that make them different and special. The teacher could highlight these differences as positive traits. School counselors could come in to the classroom once or twice a year and role-play what happens when a child is bullied. The class could talk about the emotions of victims and bullies, and ways that peers can help each other in these situations. These changes would require an incredible amount of funding and instruction time. However, bullying is pervasive and damaging to so

many of our children and adolescents. I think the time and effort spent to decrease its presence is worth it.

Implications for Research

- Nurse researchers should develop an intervention for adolescent girls with epilepsy to help them identify a personal asset or strength. This intervention should help build on that asset and assist the young women to view this asset as an important part of her identity. The research should then measure whether strengthening this asset and incorporating it into self-identity influences psychosocial outcomes like depression or anxiety.
- Teams of researchers will continue to investigate the structure and function of the adolescent brain and how it differs from the adult brain. Those interested in adolescents with epilepsy will also continue to study the influence seizure activity, hormones, and medication on brain structure and function.
- Research is needed to determine effectiveness of interventions to decrease bullying in school age and adolescent children. Numerous intervention studies are possible. They could focus on building protective factors within the individual, or developing tolerance and caring in children and teens.

Implications for Practice

- Health care clinicians including nurse practitioners, physicians, psychologists, and school social workers and counselors should be

aware that adolescent girls with epilepsy may have other life situations that are more stressful than their neurologic disease.

- These same clinicians can help adolescent girls with epilepsy to identify a strength or asset and begin to incorporate this into self-identity as a protective factor.

The question that sparked this research project was why were adolescent girls with epilepsy faring poorly psychologically? I hypothesized that the stigma that accompanies this disease created problems for these young women beyond having to cope with their neurologic disease. What I found from describing the everyday living of these four young women with epilepsy was that in certain respects, having epilepsy made life harder for them. Specifically, three of the four young women struggled academically, which is a common problem for young people with epilepsy. Elements of stigma were apparent as the young women talked about their neurologic disease. Disclosure management and information control are elements of stigma, and the young women in this study certainly wanted to control who knew about their seizures and how that person was informed.

By any name—the bullying, enacted stigma, or physical violence that Marie experienced would certainly be enough to cause anxiety, depression, or other psychological problems in any person. And for her, this enacted stigma seemed to be a direct result of having visible seizures that set her apart as being different from her peers. So I do think that having epilepsy could be a difference that would trigger adolescent peer culture to engage in enacted stigma, or

bullying, that would cause distress in the child with epilepsy. What was more surprising to me was the prevalence of bullying within adolescent peer culture *not* associated with epilepsy. In the world of adolescents, any difference can set a person apart from the dominant group. And sometimes, the exclusion occurs for no apparent reason at all.

Of course it is important to take steps to help adolescent girls with epilepsy achieve optimum mental health, academic achievement, and personal goals. Nurses, teachers, and researchers can help by developing policies that protect private health information, screening for learning and attention disorders, and facilitating strong family relationships that reward adolescent responsibility with adult privileges. Health care providers including counselors, primary care providers, and nurses can help adolescent girls with epilepsy to develop social identities that accentuate positive skills and talents.

What may be more difficult is to decrease bullying of *all* types within the existing adolescent peer culture. Because bullying occurs because of *any* perceived difference (not just epilepsy), or for no apparent reason, those who care about adolescents need to think more about changing the peer culture rather than changing or strengthening the person who is bullied. Changing the way that adolescents interact with and treat one another is a monumental task, but one that must be addressed to create and sustain a healthy social environment in which adolescents safely can learn how to become mature, responsible, productive, and emotionally happy adults.

APPENDIX A

Informational Flyer

**Teenage Girls with Epilepsy
Make a Difference!
Research Study Opportunity**

Be part of an important research study.

- Are you a girl between the ages of 13 and 18 who has epilepsy?
- Do you take at least one anti-seizure medicine?
- Do you want to help people better understand what it is like to live with epilepsy?

If you answered YES to these questions, you may be eligible to participate in a research study.

The purpose of this study is to understand what it is like to live every day as a teenage girl with epilepsy and would include three interviews over the course of two months, each lasting about an hour

Participants will receive payment for their involvement.

This study is being done by nurses from Indiana University School of Nursing.

Epilepsy Study 812-461-5238	Epilepsy Study 812-461-5238	Epilepsy Study 812-461-5238	Epilepsy Study 812-461-5238	Epilepsy Study 812-461-5238
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APPENDIX B

Informed Consent

IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Title: The Everyday Lives of Adolescent Girls with Epilepsy: A Qualitative Description

Your child is invited to participate in a research study entitled "The Everyday Lives of Adolescent Girls with Epilepsy: A Qualitative Description". The purpose of this study is to find out what everyday life is like for adolescent girls with epilepsy. Your child was selected as a possible subject by Indiana Epilepsy Services or your doctor, because she is between the ages of 13 and 18, has epilepsy, and takes at least one anti-seizure medication. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Dr. Melinda Swenson and Jessica MacLeod from the Indiana University School of Nursing.

STUDY PURPOSE

The purpose of this study is to find out what it is like to live as an adolescent girl with epilepsy.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you and your child agree to participate, your child will be one of about ten people who will be participating in this research in Evansville and / or Indianapolis, Indiana.

PROCEDURES FOR THE STUDY:

If you and your daughter agree to be in the study, your child will do the following things:

Jessica MacLeod, a student at Indiana University, will talk with your child on three occasions each about a month apart. She will ask your child about everyday experiences as an adolescent who happens to have epilepsy. Your child will be asked to talk about whatever is important to her. Your child can talk for as long or short as she wishes, but these conversations usually last about an hour. The conversation will be tape recorded and typed out later so that the researchers can study things important to girls with epilepsy. Jessica will also be taking notes in a notebook. Your child will be asked to fill out a form that has eight questions at the end of the third interview.

You and your daughter can choose whether to take part in the study or not, and you may decide to stop participating at any time, even if your child hasn't done all three interviews or filled out the eight item questionnaire. Your child will not be treated any differently by her doctor or Indiana Epilepsy Services if you choose not to participate.

RISKS OF TAKING PART IN THE STUDY:

We do not expect your child to have any problems as a result of participating in this study. The risks and potential discomforts to your child are minimal and unlikely, but could include loss of confidentiality or being identified as a research participant, psychological distress if she chooses to talk about sensitive topics, or feeling uncomfortable being audiotaped. To reduce these risks, we will keep all research records private to the extent of the law. If your child should have any discomfort during the interview, she should tell the interviewer immediately who will talk to her about her discomfort. All precautions to keep your child's information confidential will be undertaken.

BENEFITS OF TAKING PART IN THE STUDY:

There are no medical benefits to your child as a result of taking part in the study. Most people enjoy having an opportunity to talk about issues that are important to them.

ALTERNATIVES TO TAKING PART IN THE STUDY:

Should you or your child prefer not to participate in the study, your child's health care will not be affected in any way.

CONFIDENTIALITY

Efforts will be made to keep your child's personal information confidential. We cannot guarantee absolute confidentiality. Your child's personal information may be disclosed if required by law. Your child's identity will be held in confidence in reports in which the study may be published. To protect your child's identity if she participates, she will be given a false name that will be used in any discussion or publication of the research. Only Jessica MacLeod and Dr. Melinda Swenson will have access to the real identity of the study participants. All audiotapes, written transcripts, notes, and questionnaires will be kept in a locked filing cabinet in a locked office of one of the researchers. Audiotapes will be destroyed at the end of the study.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IUPUI/Clarian Institutional Review Board or its designees, study sponsor, and (as allowed by law) state or federal agencies (specifically the Office for Human Research Protections (OHRP)).

COSTS

There are no costs associated with participation in this study.

PAYMENT

Your child will receive a \$10 Simon mall gift card after completion of each interview. Therefore, if your child completes all three interviews, she would receive a total of \$30 in Simon mall gift cards.

COMPENSATION FOR INJURY

In the event of physical injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study or a research-related injury, contact the researcher Jessica MacLeod at 812-461-5238. If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949. For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You or your child may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled and will not affect the relationship the investigator has with you or your child.

SUBJECT'S CONSENT

I have been given the opportunity to ask questions about this study. Answers to such questions (if any) have been satisfactory. The information in the study records will be kept confidential and will be made available only to persons conducting the study unless I specifically give my permission to do otherwise. If the results of the study are published my child will not be identified.

In consideration of all of the above, I give my consent for my child to participate in this research study

I will be given a copy of this informed consent statement to keep for my records.

(IF SUBJECT IS A CHILD:)

SIGNATURE OF PARENT: _____ Date: _____

SIGNATURE OF PARENT: _____ Date: _____

Minor Assent (Ages 13-17)

I have been told about the study and was able to ask questions about it. My questions have been answered. I am willing to be interviewed by a nurse who will ask me what it is like to be a girl who has epilepsy. Our conversation will be audio taped. If the results of this study are published, I will not be named. I will be given \$30 in Simon mall gift cards if I complete three interviews.

SIGNATURE OF MINOR _____ Date: _____

SIGNATURE OF PERSON OBTAINING CONSENT: _____ Date: _____

APPENDIX C

Potential Conversational Openers for Open Ended Interviews

1. Tell me about a typical day in your life.
2. Tell me about a time when it really seemed to matter that you had epilepsy.
3. Tell me about a time when having epilepsy was not important.
4. Tell me what it is like to be an adolescent girl who has epilepsy.

APPENDIX D

Child Perceptions Scale

Date: / / Interviewer's Initials:
 Family No: Family Member: C Visit:

CHILD PERCEPTIONS SCALE

I would like to ask you how you feel about your seizure condition. If there is anything you do not understand, please ask me about it. Each time I will ask you to tell me how often you have these feelings, using the following responses:

Never	Not Often	Sometimes	Often	Very Often
1	2	3	4	5
1.	How often do you feel different from other kids because you have a seizure condition?			1 2 3 4 5
2.	How often do you feel people may not like you if they know you have a seizure condition?			1 2 3 4 5
3.	How often do you feel other children are uncomfortable with you because of your seizure condition?			1 2 3 4 5
4.	How often do you feel people may not want to be friends with you if they know you have a seizure condition?			1 2 3 4 5
5.	How often do you feel people would not want to go out with you or ask you to parties if they know you have seizures?			1 2 3 4 5
6.	How often do you feel embarrassed about your seizure condition?			1 2 3 4 5
7.	How often do you keep your seizure condition a secret from other kids?			1 2 3 4 5
8.	How often do you try to avoid talking to other people about your seizure condition?			1 2 3 4 5

APPENDIX E

Summary of Scores on the Child Stigma Scale

Item: How Often Do You...	Brianne Scores	Katie Scores	Rebecca Scores
1. Feel Different	3	3	2
2. Feel People May Not Like You	3	2	1
3. Feel Others Are Uncomfortable With You	2	2	2
4. Feel People May Not Want To Be Friends	5	2	1
5. Feel People May Not Want To Go Out With You	5	3	2
6. Feel Embarrassed About Your Seizure Condition	4	4	2
7. Keep Seizures A Secret	5	5	3
8. Try To Avoid Talking About Seizures	5	3	3

APPENDIX F

Fictitious Descriptions of the Participants

Brianne

At the time of her interviews, Brianne was a seventeen year old young woman. She had medium length, dark chestnut hair that hung to her shoulders. She was slender, and wore casual clothing like jeans and t-shirts. She did not wear make-up. She was a mixture of friendly and shy, and bundled up in a blanket on the couch for most interviews. She liked having the television, computer, and cell phone engaged and active during the interviews. She often took phone calls or looked at her email as we talked.

Marie

When we met, Marie was thirteen going on fourteen. She had an athletic build, similar to a gymnast, with short dark hair cut in a wedge style that was shorter in the back than the front. She wore no make-up. Our interviews occurred in the summer time, and she wore shorts, t-shirts, and tennis shoes. She was not shy, and preferred to talk to me face-to-face with consistent eye contact.

Katie

Katie was thirteen during her interviews. She was the most carefully groomed participant, usually wearing a coordinated outfit complete with matching jewelry and eye shadow, blush, and lip-stick. She liked to change her physical appearance, so she dyed her hair between interviews. At times, her hair was blond and curly and sometimes it was more reddish and straight. She told me that it often took her at least an hour to fix her hair in the morning. She was

talkative and affectionate and usually wanted to give me a hug at the end of each interview.

Rebecca

Rebecca was seventeen at the time of her interviews and presented herself as mature and capable. She was tall and slender and wore some make-up applied carefully. She had sandy colored, long hair held back in a simple pony-tail. I usually met her after her flute lesson at school. Each week, she had a private one hour flute lesson, but as I would wait for her in the hall of the school, her lesson would run over the one hour mark. It was as if she and her teacher were enjoying themselves so much that they did not want to stop. Listening to their duets was amazing, and I was impressed at Rebecca's skill and commitment to her craft.

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CURRICULUM VITAE

JESSICA S. MACLEOD

EDUCATION

Indiana University PhD in Nursing Dissertation: "The Everyday Lives of Adolescent Girls with Epilepsy: A Qualitative Description"	2009
Indiana University MSN in Nursing Major: Family Nurse Practitioner	2003
Fairfield University BSN in Nursing Summa cum Laude	1996

AWARDS

Sigma Theta Tau International Omicron Psi Chapter Research Grant Indiana University School of Nursing	2006
Alumni Association Emily Holmquist Award	2003
Indiana University Research Incentive Fellowship	2001–2002
Indiana University Graduate Fellow	2000–2001

TEACHING EXPERIENCE

University of Southern Indiana Instructor of Nursing Graduate faculty member in MSN Family Nurse Practitioner Program Undergraduate faculty member in BSN Program	2004–2007
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CLINICAL EXPERIENCE

Family Medicine Associates, Evansville, IN Family Nurse Practitioner Provides primary care to patients in a family practice setting	2003–present
University of Evansville Student Health Center, Evansville, IN Registered Nurse Triaged the care of college students in a primary care setting	August 1999 – April 2001

Newton House Nursing Home, Grantham, England
Registered Nurse August 1998–March 1999
Provided nursing care to elderly patients with
dementia

Yale-New Haven Hospital, New Haven, CT
Registered Nurse August 1996–July 1998
Provided nursing care to adult patients on a renal
medicine and telemetry in-patient unit

PUBLICATIONS

Hoebeke, R., & MacLeod, J. S. (2006). Faculty clinical site visits versus preceptor evaluation of NP students. *The Journal for Nurse Practitioners*, 2, 316–317.

Austin, J. K., MacLeod, J. S., Dunn, D. M., Shen, J., & Perkins, S. M. (2004). Instruments to measure stigma in children with epilepsy and their parents: initial development and testing. *Epilepsy & Behavior*, 5, 472–482.

MacLeod, J. S., & Austin, J. K. (2003). Stigma in the lives of adolescents with epilepsy: a review of the literature. *Epilepsy & Behavior*, 4, 112–117.

Swenson, M. M., MacLeod, J. S., Williams, S. D., Miller, A. M., & Champion, V. L. (2003). Quality of living among ovarian germ cell cancer survivors: a narrative analysis. *Oncology Nursing Forum*. May/June Online Exclusive.

PRESENTATIONS

MacLeod, J. S., & Burger, J. (2006). *Using community engagement to teach evidence based nursing practice*. 11th Annual Nursing and Health Professions Educator Conference. University of Southern Indiana. October 18, 2006.

Burger, J., & MacLeod, J. S. (2006). *Novel approach to increasing cultural awareness in novice nursing students*. 11th Annual Nursing and Health Professions Educator Conference. University of Southern Indiana. October 18, 2006.

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