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by
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Examining Perceived Stigma of Children with Newly-Diagnosed Epilepsy and Their Caregivers Over a Two-Year Period
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Chapter I: Review of the Literature

Pediatric Epilepsy

Seizures and pediatric epilepsy. In the United States, approximately 5% of children and adolescents (from this point on, “children” will include all individuals under the age of 18) will experience a seizure before reaching adulthood, however many of these children will not continue on to develop epilepsy (Hauser & Banerjee, 2008). A seizure is a brief, excessive discharge of brain electrical activity which occurs when the brain continues to abnormally fire neurons instead of returning to homeostasis (Devinsky, 2008). A large number of seizures experienced by children are fever-induced (febrile seizures) and non-epileptic (Epilepsy Foundation, 2011). Epilepsy is a neurological disorder characterized by two or more unprovoked seizures (National Institute of Neurological Disorders and Stroke [NINDS], 2011). Because at least two seizures are required to diagnose epilepsy, once a child experiences a seizure, he/she is closely monitored for the occurrence of additional seizures. If an additional seizure occurs, then the child is diagnosed with epilepsy and treatment is started (NINDS, 2011).

Prevalence of pediatric epilepsy. Epilepsy is one of the most prevalent pediatric neurological conditions, affecting approximately 326,000 children under the age of 15 in the United States (Begley et al., 2000). Fifty to sixty percent of individuals with epilepsy are diagnosed prior to the age of 16 (Weaver, 2001). About 25% of the children who experience a seizure before reaching adulthood will develop epilepsy (Hauser & Banerjee, 2008). Although genetic abnormalities may only contribute to a fraction of
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individuals with epilepsy, having a parent with epilepsy increases a child’s risk for developing epilepsy (Hauser & Banerjee, 2008). By age 25, a child of a parent with epilepsy has a 6% chance of experiencing a seizure compared to 1-2% in the general pediatric population (Devinsky, 2008). Finally, epilepsy is slightly more common in males than in females (Devinsky, 2008).

**Types of pediatric epilepsy.** Epilepsy types are classified by identifying the area of the brain affected by the abnormal electrical charges that cause the seizure. There are two broad areas of seizure classification: localization-related and generalized. Localization-related seizures, formally called partial seizures, refer to seizures that are focused in one hemisphere of the brain. In the past, localized seizures were further classified as simple or complex; however recent guidelines have eliminated this further classification because the terms “simple” and “complex” are often misused and misunderstood (Commission on Classification and Terminology of the International League Against Epilepsy [ILAE], 2010). Instead localization-related seizures are further described by the features that are most useful for a specific purpose (e.g., describing degree of cognitive impairment for neuropsychological research) (Commission on Classification and Terminology of the ILAE, 2010). Generalized seizures originate in and engage both sides of the brain. Generalized seizures include absence (staring spells), atonic, myoclonic, tonic, clonic, and tonic-clonic seizures (Williams, 2004).

From a psychosocial vantage point, it is important to understand the level of visibility of each seizure type (Jones et al., 1984; Quinn & Chaudoir, 2009). Tonic-clonic seizures have the most dramatic presentation and are by far the most visible to others (Victor & Ropper, 2001). These seizures are characterized by a loss of consciousness
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where the muscles will become tense (tonic phase) followed by a period where the
muscles will contract and relax to cause convulsions (clonic phase). The least visible
seizures are absence seizures. These seizures are characterized by a brief moment of
impaired consciousness in which a child appears to be daydreaming or not listening. The
visibility of the remaining seizures falls somewhere between tonic-clonic and absence
seizures (Victor & Ropper, 2001).

Causes of pediatric epilepsy. Epilepsy can occur for a variety of reasons and
often the origin of pediatric epilepsy is unknown. As many as 60-80% of newly-
diagnosed children with epilepsy have idiopathic epilepsy, meaning there is no
identifiable cause (Hauser & Banerjee, 2008). Other epilepsy classifications include
symptomatic (cause of the disorder is identifiable) and cryptogenic (cause of the disorder
is unknown but is presumed symptomatic) (Commission on Classification and
Terminology of the ILAE, 1989). Current ILAE guidelines for classification are
changing; however these guidelines have not yet been systematically implemented and
thus are beyond the scope of this literature review (Commission on Classification and
Terminology of the ILAE, 2010).

Treatment options and pediatric epilepsy. The most common treatment for
epilepsy is the use of anti-epileptic drugs (AED) (Weaver, 2001). Nearly 75% of
children with epilepsy gain seizure control by using AEDs (Kneen & Appleton, 2006).
There are over 20 different AEDs used in children with epilepsy to gain seizure control.
Each of the different medications affects different brain mechanisms, and thus certain
AEDs are more appropriate for certain types of seizure control
(epilepsy.com/professionals, 2011). In the United States, it is typical for pediatric
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patients to remain on AEDs until they are seizure free for 2 years; however some epilepsy
types (especially those that are symptomatic or cryptogenic) may require lifelong AED
treatment (Shinnar & Pellock, 2002).

The two most frequently used non-medication treatments for pediatric epilepsy
are surgery and the ketogenic diet. Both of these treatments are only utilized after a
pediatric patient has tried and failed to gain seizure control through the use of AEDs
(Weaver, 2001).

**Chronicity and prognosis of pediatric epilepsy.** The prognosis for seizure
control for many children with epilepsy is good. After pediatric patients have been
diagnosed with epilepsy and AED treatment is started, approximately two-thirds of
patients will remain seizure free for five years (Devinsky, 2008). Although it is typical in
the United States to withdraw AED treatment once a child has remained seizure free for 2
years, 20-35% of pediatric patients will relapse and experience additional seizures
(Shinnar & Pellock, 2002).

**Psychological comorbidities of pediatric epilepsy.** Researchers have found that
children with epilepsy often experience comorbid psychological conditions. Children
with epilepsy often have impaired academic performance and lower IQ scores than
children without epilepsy (Salpekar & Dunn, 2007). Twenty to thirty percent of children
with epilepsy are also diagnosed with attention deficit-hyperactivity disorder (ADHD)
and 20% of children with epilepsy are diagnosed with learning disorders (Williams,
2004). Children with epilepsy who have active seizures are more likely to have
behavioral problems than children with inactive seizures (Funderburk, McCormick, &
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Austin, 2007). Additionally, children with epilepsy are at a greater risk for developing depression and anxiety (Salpekar & Dunn, 2007).

**Psychosocial difficulties and pediatric epilepsy.** Children with epilepsy are at an increased risk for experiencing poor psychosocial outcomes. For example, researchers have found that children with epilepsy are bullied more often than both their healthy classmates (Hamiwka et al., 2011), and children with other chronic medical conditions (Austin, Shafer, & Deering, 2002). Additionally, Hirfanoglu et al. (2009) found that children with epilepsy report feeling stigmatized and ashamed because of their illness.

**Stigma**

Current stigma research can trace its roots to Goffman’s (1963) conceptualization of stigma. According to Goffman (1963), stigma refers to an attribute that a person possesses which is deeply discrediting, represents undesired differentness, and reduces the stigmatized from a whole person to a tainted, discounted “other.” Goffman (1963) also indicated that in order for an individual to be stigmatized, he/she must be a person who possesses low social status and an attribute that conveys a negatively valued social identity.

Researchers have begun to examine the clinical utility of Goffman’s (1963) definition of health-related stigma. Specifically, Goffman’s (1963) understanding of stigma as being a “spoiled identity” and social exclusion are relevant to modern health-related stigma; whereas other concepts such as “abominations of the body” (physical deformities), “blemishes of character” (weak will, passions, treacherous and rigid beliefs, and dishonesty), and “tribal identities” (stigmatized conditions based on race, sex, religion, and national origin) are less relevant (Weiss, Ramakrishna, & Somma, 2006).
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Instead, researchers concerned with health-related stigma indicate that stigma should refer to a social process, which can be experienced or anticipated, and consists of "exclusion, rejection, blame or devaluation that results from experience....or anticipation of an adverse social judgment" (Weiss et al., 2006). This judgment is based on a health problem or health-related condition and is medically unwarranted (Weiss et al., 2006).

Additional concepts which may capture the way children experience stigma include negative peer relationships, bullying, and teacher rejection. Negative peer relationships include not having reciprocal friendships with peers and children not wanting to be friends with a particular child (Greco, Freeman, & Dufton, 2007; Kashikar-Zuck et al., 2007; Noll et al., 1996, 2007, Noll, Reiter-Purtill, Vannatta, Gerhardt, & Short, 2007; Vannatta et al., 2008; Zeller, Reiter-Purtill, & Ramey, 2008). Bullying refers to more severe forms of peer rejection in which children are either physically, verbally, or relationally attempting to hurt someone else (Cleave & Davis, 2006; Hamiwka et al., 2011; Hunt, Burden, Hepper, Stevenson, & Johnston, 2006, 2007; Storch et al., 2007; Williams & Chapman, 2011). Finally, teacher rejection refers to teachers' dislike or discomfort with certain students (Prpic et al., 2003).

**Types of stigma.** The concept of stigma can be divided into two parts: enacted and felt. Enacted stigma refers to the actual observed episodes of discrimination by others on the grounds of being socially flawed (Jacoby & Austin, 2007; Scambler, 2009). For example, a child with HIV being denied a position on the baseball team because the coach is afraid that the other teammates will somehow “catch HIV.” Felt or perceived stigma is the internalized sense of shame that occurs from possessing a stigmatized attribute and the anticipation that others will discriminate against the stigmatized
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An example of felt stigma may be a child with irritable bowel syndrome (IBS) hiding the illness from his/her classmates in fear of others thinking that he/she is somehow “disgusting.”

Factors influencing stigma. Past researchers have identified six dimensions which influence the extent to which an individual is stigmatized (Jones et al., 1984). These six dimensions include course, disruptiveness, aesthetic qualities, origin, peril, and concealability. The course of a condition refers to the pattern of change that the condition displays over time and the ultimate outcome that an individual has from possessing the condition. The disruptiveness of a condition refers to the extent to which the condition blocks or hampers interaction and communication. The aesthetic quality of a condition refers to the extent to which the mark makes the individual repellant, ugly, or upsetting. The origin of a condition refers to the circumstances under which the condition originated and if anyone can be held responsible for the condition. Peril refers to the danger which is posed by the mark and how imminent and serious the danger is. Finally, concealability of a condition refers to the extent that a stigmatized condition is able to be hidden and the extent that a stigmatized condition’s visibility can be controlled (Jones et al., 1984). It is important to note that some conditions may always be visible (i.e. Down Syndrome, obesity), some conditions can always be concealed unless chosen to disclose (i.e. congenital heart condition), and some conditions are plagued by episodic visibility (i.e. epilepsy, asthma).

Quinn & Chaudoir (2009) identified four stigma components which influence the level of stigma that individuals with a concealable stigma experience. These components include 1) anticipated stigma (i.e., level of prejudice and devaluation an individual
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expects to experience), 2) centrality of the condition (i.e., how significant the condition is in the life of the individual), 3) saliency of the condition (i.e., how central the condition is to the individual’s identity), and 4) level of devaluation from the greater culture (i.e., how much the condition is look down upon by the culture in which the individual lives) (Quinn & Chaudoir, 2009).

Effects of stigma. Stigma can impact individuals in a variety of ways. Researchers have demonstrated that individuals who experience stigma are at an increased risk for developing depression. Reisinger & Dilorio (2009) found that stigma was a significant predictor of depressive symptoms among adults with epilepsy. In this study, 319 adults with epilepsy were administered self-report measures of depression and stigma at three time points (e.g., baseline, 3 month follow-up, and 6 month follow-up). Results revealed a significant positive relationship between stigma and depressive symptoms at all three time points. In a related study, Leaffer et al (2011) examined the relationship between stigma and lifetime history of depression in adults with epilepsy over two time points (e.g., baseline and 1 year follow-up). Results demonstrated that presence of depressive symptoms was associated with increased stigma at baseline and one year later. It is unknown if individuals in this study experienced depressive symptoms prior to developing epilepsy.

Funderburk et al. (2007) demonstrated that stigma may impact the way that individuals view themselves. In this study, 173 children with epilepsy were administered self-report measures of self-concept and perceived stigma. Results demonstrated that children with higher levels of perceived stigma had lower self-concepts. Another study of seventy adults with mental illness assessed self-esteem and perceived stigma over
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three time points (e.g., baseline, 6 month follow-up, and a 24 month follow-up) (Link, Struwing, Neese-Todd, Asmussen, & Phelan, 2001). Results demonstrated that high levels of perceived stigma were associated with low levels of self-esteem and that high levels of perceived stigma at baseline could predict low levels of self-esteem at both 6 and 24-month follow-ups.

Individuals' social lives may be negatively impacted by stigma. In a qualitative study exploring stigma and discrimination with 30 adults with epilepsy, researchers found that adults with epilepsy feel excluded from the possibility of marriage, feel rejected from many places of employment, and often restrict social activities for fear of encountering negative attitudes from others (Rhodes, Small, Ismail, & Wright, 2008).

In addition, individuals who feel stigmatized report experiencing a lower overall quality of life (QOL). Recent data with adults with depressive disorders found a negative relationship between perceived stigma and overall QOL (Cheng-Fang et al., 2009). In this study, 229 adults with depressive disorders completed self-report measures of perceived stigma and QOL. Results demonstrated that individuals who reported high levels of perceived stigma also reported poor QOL. In a similar study, McLaughlin, Pachana, and McFarland (2009) found that stigma was the strongest predictor of poor health-related quality of life (HRQOL).

Stigma may be related to negative physical health implications. Research has demonstrated that individuals who are stigmatized are at an increased risk for developing physical problems such as heart disease and stroke (Major & O'Brien, 2005). Stigmatized individuals may be affected directly by being exposed to more harmful physical and social environments and by being less likely to access high quality health
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care. They may be affected indirectly by experiencing negative physiologic and psychological threat responses which can contribute to health problems (Major & O’Brien, 2005).

Individuals who feel stigmatized may also be less confident in their ability to manage their illness. One study of 314 adults with epilepsy demonstrated that high levels of perceived stigma were related to low levels of self-efficacy for management of their illness (Dilorio et al., 2003). Similarly, Buston and Wood (1999) examined the relationship between non-adherence with medical treatment and perception of stigma. In this study utilizing structured interviews, children with asthma (n=49) reported that a major contributor to non-adherence with their medical treatment was fear of being teased or embarrassed by others (Buston & Wood, 1999).

Stigma measurement. Stigma is difficult to measure due to the lack of a cohesive definition of what stigma actually encompasses. Stigma is defined as both something that happens to someone (enacted stigma) and fear or anticipation of something happening to someone (perceived stigma) because an individual possess a quality that is understood by society as undesirable (Goffman, 1963; Jacoby & Austin, 2007; Scamber, 2009). It can be studied by examining an individual’s actual experience with discrimination or asking individuals about feelings of shame, fear, and guilt associated with their (potentially) stigmatizing condition (van Brakel, 2005). Stigma can also be studied by asking community members and healthcare providers about their attitudes and beliefs about a (potentially) stigmatizing condition or reviewing legislation, news coverage, and health services for stigmatizing and discriminatory practices (van Brakel, 2005).
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Both qualitative and quantitative methods have been used to measure stigma. Qualitative methods can consist of interviews, focus groups, and participant observations (van Brakel, 2005). Focus groups have been used to study perceived stigma and experiences of discrimination in individuals with Hepatitis C (Janke, McGraw, Garcia-Tsao, & Fraenkel, 2006), structured interviews to study stigma, shame, and blame of individuals with lung cancer (Chapple, Ziebland, & McPherson, 2004), and semi-structured interviews to study stigma and discrimination with individuals who are obese (Thomas, Hyde, Karunaratne, Herbert, & Komesaroff, 2008).

Quantitative methods consist of questionnaires and stigma scales. Questionnaires can consist of both closed and open-ended questions and have been used to examine the general public's attitudes about individuals with epilepsy (Dilorio et al., 2004), nurses' willingness to provide care to individuals with human immunodeficiency virus (HIV) (Dubbert, Kemppainen, & White-Taylor, 1994), and primary care physician's knowledge, attitudes, and beliefs regarding children with obesity (Gerwen, Franc, Rosman, Vaillant, & Pelletier-Fleury, 2008). Stigma scales are designed to measure level of stigma severity and have been used to examine stigma in adults with Alzheimer's disease, amyotrophic lateral sclerosis (ALS), epilepsy, Parkinson's disease, stroke (Rao et al., 2009) and obesity (Lillis, Luoma, Levin, & Hayes, 2010).

Research measuring health-related stigma in pediatric epilepsy is scarce. Qualitative studies using focus groups have been conducted to examine the impact of epilepsy on quality of life in children (Moffat, Dorris, Connor, & Espie, 2009). Disease specific stigma scales have been developed to measure perceived stigma in both children with epilepsy and their parents (Austin, MacLeod, Dunn, Shen, & Perkins, 2004). Also,
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generic stigma scales have been used with children with chronic diseases to measure both
the child’s attitude toward his/her illness (Heimlich, Westbrook, Austin, Cramer, &
Devinsky, 2000) and the parent’s attitude towards the child’s illness (Austin et al., 2008).

An important issue regarding the measurement of stigma in children is whether
the respondent is the child or the child’s caregiver (e.g. parent-proxy measurement).
Parent-proxy measures are designed to be used as a substitute for child self-report
measures when children are too sick/too weak to fill out questionnaires and/or when
children have limited cognitive or communication abilities and may not be able to
articulate their experiences (Ronen, Streiner, Rosenbaum, & the Canadian Pediatric
Epilepsy Network, 2003). Most children who are eight years of age or older are able to
accurately reflect on their experiences; however parents continue to complete parent-
proxy measures of their child’s emotional and psychosocial processes in both research
settings and clinical practice (Riley, 2004).

It is pertinent to examine level of congruence between child and parent reports of
perceived stigma because initiation and type of mental health treatment are often
contingent upon whether or not a caregiver believes that his/her child is experiencing
distress. When a child feels that he/she is being stigmatized but his/her parent disagrees,
the child may not receive the necessary services to help ease the burden of feeling
stigmatized. Also if a child does not feel like he/she is being stigmatized but his/her
parent disagrees, then the child may receive unnecessary or inappropriate services.

Although studies have employed both child and parent reports of perceived
stigma (Hirfanoglu et al., 2009; Ronen, Rosenbaum, Law, & Steiner, 1999), only one
pediatric study has examined the congruence between the two reports (Lawrence,
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Rosenberg, Mason, & Fauerbach, 2011). This study was conducted with 85 pediatric burn survivors and their parents. Results from the study demonstrated high parent-child agreement when children reported low levels of perceived stigma and low parent-child agreement when children reported high levels of perceived stigma (Lawrence et al., 2011). These findings suggest that parents may be unaware of their children’s perception of health-related stigma; however more research is needed to better understand the level of congruence between child and parent reports of perceived stigma.

Although few studies have examined parent-child agreement of perceived stigma in pediatric diseases, an extensive amount of research has examined parent-child agreement in similar constructs, such as child HRQOL. Findings demonstrate that level of agreement between parent and child reports may be affected by the specific aspects of health that are being studied. For example, studies have demonstrated less parent-child agreement for internal, emotional and psychosocial factors such as perceived stigma when compared to concrete, external factors such as physical health (Upton, Lawford, & Eiser, 2008; Verhey et al., 2009).

A final measurement issue which needs to be addressed is the lack of longitudinal studies on health-related stigma with pediatric patients. Health-related stigma is typically studied using a cross-sectional sample of individuals with varying lengths of time since diagnosis (Austin et al., 2004; Heimlich et al., 2000; Lillis et al., 2010; Rao et al., 2009; van Brakel, 2005). The lack of longitudinal studies on health-related stigma makes it difficult to understand the course of stigma following diagnosis. One vantage point is that as individuals become better adjusted to their illness their stigma decreases.
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Stigma and Epilepsy

Research has demonstrated that individuals with epilepsy may be at-risk for experiencing social difficulties, particularly in relation to stigma (Jacoby & Austin, 2007).

**Stigma and adults.** Adults with epilepsy often rate stigma as one of the most unpleasant facets of having epilepsy (Fisher et al., 2000). Specifically, 1,023 adults with epilepsy were surveyed about their perceptions and subjective experiences with epilepsy. Results indicated that 24% of individuals rated social stigma as the worst aspect of having epilepsy. Notably, only 50% of individuals reported complete seizure control, while the other 50% reported somewhat, slight, or no seizure control. It is possible that individuals who reported stigma as the worst aspect of epilepsy were also individuals who did not have sufficient control of their seizures (Fisher et al., 2000).

Feelings of stigmatization may also be affected by geographic location and culture. In a relatively recent study in Korea conducted by Lee, Yoo, and Lee (2005), 31% of individuals with epilepsy reported feeling stigmatized and 9% of individuals reported feeling highly stigmatized. In a similar study conducted in 15 different European countries, 51% of individuals with epilepsy reported feeling stigmatized with 18% of individuals feeling highly stigmatized (Baker, Brooks, Buck, & Jacoby, 2000). Analogous studies have not been conducted in the United States.

**Stigma and children.** Research with pediatric patients with epilepsy is scarce and therefore little is known about the influence of stigma on children with epilepsy (MacLeod & Austin, 2003). Past research has demonstrated long-term impacts of experiencing stigma such as, increased depression, poor self-concept, low overall quality
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of life, and low perception of ability to manage illness (Cheng-Fang et al., 2009; DiLorio et al., 2003; Funderburk et al., 2007; Leaffet et al., 2011; Weiss et al., 2006); however it is unknown if these results generalize to pediatric epilepsy. Stigma studies have examined what other people think about children with epilepsy, as well as what children with epilepsy think about themselves.

Teacher and peer perception. One study found that teacher perceptions of children with epilepsy are generally negative (Prpic et al., 2003). Specifically, researchers examined 216 teachers’ opinions and beliefs regarding children with epilepsy by utilizing self-report questionnaires. All teachers had worked with at least one child with epilepsy and the average number of children with epilepsy that one teacher had taught was 3 to 4. Results demonstrated that nearly half of teachers questioned believed that children with epilepsy differ from healthy children by their behavior, 26 percent believed that children with epilepsy are not able to achieve excellent school results, and 36 percent of the teachers were not confident in their approach to teach and work with children with epilepsy (Prpic et al., 2003).

To better understand children’s opinions about individuals with epilepsy, a large survey study of 19,441 community high school students was conducted (Austin et al., 2002). Results from this study indicated that 37 percent of children believed that children with epilepsy are more likely to get picked on or bullied and 26 percent of children were unsure if having epilepsy would make you more likely to get picked on or bullied. With regards to popularity, 13 percent of children surveyed believed that having epilepsy would make you unpopular and 45 percent of children were unsure if having epilepsy would make you unpopular (Austin et al., 2002).
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In a study designed to examine the social impact of epilepsy compared to other medical conditions, Cheung and Wirrell (2006) employed qualitative methods to examine children’s opinions of individuals with epilepsy and other medical conditions. In this study, researchers used structured interviews to ask children with and without chronic illnesses their perception of children with various chronic medical conditions. Forty-one children without a chronic medical condition, 32 children with epilepsy, 38 children with asthma, 21 children with diabetes, and 17 children with chronic migraines were asked questions regarding the physical and social impact of various chronic medical conditions. Participants were also questioned about their willingness to befriend an individual with each of these medical conditions. Results of this study demonstrated that epilepsy was found to have a significantly greater social impact than asthma, diabetes, arthritis, and migraine and a similar social impact as HIV and leukemia. Interestingly when compared to unaffected children, children with epilepsy perceived their condition to have significantly less social impact (Cheung & Wirrell, 2006).

Child perception. Qualitative methods have also been used to examine children’s experiences of having epilepsy. One study conducted focus groups with children with epilepsy and their parents in order to identify the burdens and concerns of epilepsy (Ronen et al., 1999). Results from this study indicated that one of the most common concerns with children was how they were perceived by others. Some of the statements made by children included “they treat me different, they like, they ignore me sometimes” and “friends...sometimes they would call me ‘stupid, get away, loser.’” Although it is clear that these children are concerned about how others perceive them, what is unclear is whether their concern is due to having epilepsy, or other factors (Ronen et al., 1999).
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In a study conducted by Westbrook, Bauman, and Shinnar (1992), a cross-sectional sample of 64 adolescents (12-20 years old) with epilepsy were instructed to complete self-report questionnaires of stigma, disclosure management, and self-esteem. Results demonstrated that most adolescents believed that having epilepsy did not influence their social lives, however many adolescents indicated that they were sometimes reluctant to tell others that they have epilepsy (Westbrook et al., 1992). In addition, 66 percent adolescents reported that having epilepsy did not affect whether or not people wanted to be friends with them, 60 percent of adolescents reported that having epilepsy did not affect whether people liked them, and 69 percent of adolescents reported that having epilepsy did not affect whether they were asked to go out on dates or go to a party. In contrast, 53 percent of adolescents reported that they often or sometimes keep their epilepsy a secret. The mixed results may be due to adolescents wanting to believe that their illness has less social impact than it really does or it may be due to adolescents not feeling the need to disclose their medical history to others. Also, it is possible that these adolescents really did not feel stigmatized. While this study provides some insight into the stigma experienced by adolescents with epilepsy, it has some limitations. First, it is impossible to tell if the 53 percent of adolescents who abstained from disclosing their illness to others are the same or different adolescents than the majority of adolescents who indicated that stigma did not affect them. Also, it is unclear whether those individuals who reported not feeling stigmatized were adolescents who were no longer experiencing seizures.

In a related study, perceptions of epilepsy were examined among children with epilepsy and their parents (Hirfanoglu et al., 2009). In this cross-sectional study
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conducted in Turkey, 220 children with epilepsy (8-17 years old) and 313 of their parents were administered self-report and parent-report questionnaires on knowledge, attitudes, and beliefs about epilepsy. Results from this study indicated that many children and parents were worried about the potentially stigmatizing aspect of having epilepsy. Forty-one percent of children reported feeling stigmatized by their friends and 20 percent of children indicated that epilepsy is a “shameful” condition. Additionally, 19 percent of children reported that epilepsy limited their social activities and 65 percent of parents wondered whether epilepsy would restrict their child’s future life in terms of finding a marriage partner, obtaining and keeping a good job, and enjoying normal activities (Hirfanoglu et al., 2009).

Summary of existing literature and limitations

Few studies have examined the perception of stigma among children with epilepsy and to date no studies have examined the course of perceived stigma after diagnosis. Of the existing literature, researchers have found contradictory results regarding the extent to which children with epilepsy anticipate being stigmatized (Hirfanoglu et al., 2009; Ronen et al., 1999; Westbrook et al., 1992). One limitation of existing literature is that it is cross-sectional and includes participants from a diverse range of time since diagnosis, and thus conclusions cannot be drawn about the course of children’s perception of epilepsy-related stigma. Another limitation is the absence of studies addressing parent-child agreement of perceived stigma among children with epilepsy, and only one pediatric study examining this concept outside of epilepsy (Lawrence et al., 2011). Finally it is unclear whether the presence or absence of active seizures influences the perception of epilepsy-related stigma. While several studies
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regarding stigma also measure seizure control/freedom, these studies have not examined
the impact of seizure status on perceived stigma (Fisher et al., 2000; McLaughlin et al.,
Chapter II: Rationale and Hypotheses

Children with epilepsy, of which there are approximately 326,000 children under the age of 15 in the United States, are at high risk for stigma (Begley et al., 2000; Jacoby & Austin, 2007). Long-term impacts of experiencing stigma (i.e., the exclusion, rejection, blame or devaluation that results from experience or anticipation of an adverse social judgment) include increased depression, poor self-concept, low overall quality of life, and low perception of ability to manage illness (Cheng-Fang et al., 2009; Dilorio et al., 2003; Funderburk et al., 2007; Leafer et al., 2011; Weiss et al., 2006). Few studies have examined the perception of stigma (i.e., the internalized sense of shame that occurs from possessing a stigmatized attribute and the anticipation that others will discriminate against the stigmatized individual) among children with epilepsy (Jacoby & Austin, 2007). One perspective is that as children become better adjusted to their diagnosis their perception of stigma decreases. Cross-sectional research has concluded that children with epilepsy feel stigmatized by their peers and are worried about how others perceive them (Hirfanoglu et al., 2009; Ronen et al., 1999). To date, no studies have examined changes in perceived stigma over time.

Not every child with epilepsy will experience epilepsy-related stigma and it is unclear why some children feel stigmatized while other children do not. One potential difference may be that epilepsy is more salient to children with active seizures than children who have been seizure-free for an extended period of time. Children with active seizures have less control over their decision to conceal their illness, which may be a
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contributing factor of stigma (Jones et al., 1984; Quinn & Chaudoir, 2009). While several studies regarding stigma also measure seizure control/freedom, these studies have not examined the impact of seizure status on perceived stigma (Fisher et al., 2000; McLaughlin et al., 2009; Westbrook et al., 1992).

When conducting research with children, it is important to address level of congruence between child and parent reports. Initiation and type of mental health treatment are often contingent upon whether or not a parent believes his/her child is experiencing distress. When a child feels that he/she is being stigmatized but his/her parent disagrees, the child may not receive the necessary services to help ease the burden of feeling stigmatized. Research conducted outside of pediatric epilepsy has found that children report higher perceived stigma than their parents, and parent-child agreement is poor when children report high levels of stigma (Lawrence et al., 2011). Also, studies have demonstrated less parent-child agreement for internal, emotional and psychosocial factors such as perceived stigma when compared to concrete, external factors such as physical health (Upton et al., 2008; Verhey et al., 2009). Little is known about parent-child agreement of perceived stigma and to date no studies have examined this construct in pediatric epilepsy.

The aims of the current study are to: 1) examine the course of perceived epilepsy-related stigma among children and their caregivers 2) examine the influence of seizure absence/presence on children and caregivers’ perception of epilepsy-related stigma. And 3) examine the congruence of child and caregiver perception of child epilepsy-related stigma. It is hypothesized that children and their caregivers will report decreasing amounts of epilepsy-related perceived stigma from baseline (within 1 month after
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diagnosis) to two years later. It is hypothesized that children with active seizures and
their caregivers will experience higher epilepsy-related perceived stigma between one
year and two years post-diagnosis than children without active seizures. Finally, little is
known about parent-child agreement of perceived stigma; therefore no formal hypotheses
will be made regarding level of congruence between caregiver and child reports of
epilepsy-related perceived stigma. Thus, exploratory analyses will be conducted
examining the correlation between caregiver-reported epilepsy-related perceived stigma
and child-reported epilepsy-related perceived stigma.
Chapter III: Method

Design

The current study is a longitudinal study and will include data collected over a two year period. This study includes data from caregivers of children with epilepsy (ages 2-12 years) and of children 8 years of age and older. All data were gathered between 2006 and 2011 and were part of a larger NIH-funded study examining adherence patterns and barriers to treatment of children newly-diagnosed with epilepsy.

Participants

Inclusion criteria for the larger study included 1) children with newly diagnosed epilepsy (i.e. recruited on the day of diagnosis) 2) children between the ages of 2-12 years, and 3) participants’ ability to speak/write English for the completion of questionnaires. Exclusion criteria for the larger study included 1) children with a caregiver-reported developmental disorder and 2) children with a comorbid medical diagnosis requiring daily medications.

The current study will include data of 97 caregivers of children with newly-diagnosed epilepsy. An additional inclusion criterion for the current study was completion of the baseline Parent Stigma Scale. Of the n=110 eligible participants, one-hundred and five families agreed to participate in the larger study. However, only data of 97 participants were included in the current study due to the following reasons: two did not return to clinic after diagnosis, one terminated participation in the study due to being seen in another clinic, and five participants had missing questionnaire data at baseline.
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Thus, the current participant cohort included data of 97 caregivers of children with newly-diagnosed epilepsy (mean age = 35.63 ± 6.97, 79.4% mothers, and 82.5% Caucasian) (see Figure 1 for caregiver participant recruitment details). Their children had a mean age of 7.14 ± 2.87, were 60.8% male, and 76.3% Caucasian. See Table 1 for complete participant demographics and medical variables.

The current study will also include data from 39 children with epilepsy, all of whom were newly-diagnosed with epilepsy and eight years of age and older. Additional inclusion criteria for the current study included children aged 8 years and older (at baseline) and completion of the baseline Child Stigma Scale. Of the n=46 eligible child participants, only data of 39 child participants were included in the current study due to the following reasons: two did not return to clinic after diagnosis, two had caregivers who did not want their children to complete questionnaires, one did not complete questionnaires due to having a learning disability and being unable to comprehend the questionnaires, and one terminated participation from the study due to being seen in another clinic. Thus, the current child cohort included data of 39 children with newly-diagnosed epilepsy with a mean age of 9.95 ± 1.40, who were 51.3% male, and 79.5% Caucasian (see Figure 2 for child participant recruitment details). With regards to seizure type, 51.3% of participants had localization-related seizures, 33.3% had generalized seizures, and 15.4% had unclassified seizures. Additionally, 66.7% of children had convulsive seizures (it is important to note that the presence of convulsive/non-convulsive seizures is not mutually exclusive from seizure type).
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Measures

Parent Stigma Scale. The Parent Stigma Scale (Austin et al., 2004) is a five-item instrument designed to measure caregivers’ belief that their child is experiencing stigma or will experience stigma from having epilepsy. Caregivers are instructed to respond to five items on a five-point scale ranging from 1 (strongly disagree) to 5 (strongly agree). Item scores are summed and then averaged for a total stigma score (range 1-5), with higher scores representing greater perceived epilepsy-related stigma. For example, if a parent reported two 3s, a 2, a 4, and a 5 for each of the five items then the total stigma score would be calculated as follows (3+3+2+4+5)= 17/5(# of items) = 3.4.

Prior research has validated the use of the Parent Stigma Scale to evaluate caregivers’ perception of stigma associated with their child having epilepsy (Austin et al., 2004). Internal reliability of the measure has been established, with reported coefficient alphas ranging from 0.77 for the newly diagnosed sample and 0.79 for the chronic sample. Corrected item-to-total correlations ranged from 0.50 to 0.64 in the newly diagnosed sample and 0.52 to 0.70 in the chronic sample. Coefficient alpha for the current study was 0.71 at baseline.

Child Stigma Scale. The Child Stigma Scale (Austin et al., 2004) is an eight-item instrument designed to measure children’s belief that they are experiencing or will experience stigma from having epilepsy. Children are instructed to respond to the eight items on a five-point scale ranging from 1 (strongly disagree) to 5 (strongly agree). Item scores are summed and then averaged for a total stigma score (range 1-5), with higher scores representing greater perceived epilepsy-related stigma. For example, if a child
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reported two 4s, two 3s, a 2, two 1s, and a 5 on the eight items then the total stigma score
would be calculated as follows \((4+4+3+3+2+1+1+5)= 23/8 \text{ ( # of items) } = 2.88\).

Prior research has validated the use of the Child Stigma Scale to evaluate
children’s perception of stigma associated with having epilepsy (Austin et al., 2004).
Reported coefficient alpha for a sample of children with chronic epilepsy was 0.81 and
corrected item-to-total correlations ranged from 0.44 to 0.65. Coefficient alpha for the
current study was 0.81 at baseline.

Seizure Status. Presence or absence of seizures was collected through medical
chart review and parent report of the following questions 1) “how many seizures has your
child had since their last clinic visit” and 2) “since your last clinic visit, have you noticed
seizure activity or staring spells.” Children experiencing one or more seizures and/or
staring spells were categorized as 1= seizures present, while those with no reported
staring spells or seizures were categorized as 0 = seizures absent.

Background Information Form. The Background Information Form was
completed by caregivers and contained information regarding family composition, child’s
age, race, and sex, and caregivers’ age, race, sex, marital status, education, and
occupation.

Procedure

For the larger study, families meeting inclusion criteria were approached by
trained research staff during their regular epilepsy clinic appointment (i.e. at diagnosis).
A brief explanation was given to families that the purpose of the study was to gain an
understanding of how children with epilepsy take their anti-epileptic drugs (AEDs) and
the factors that interfere with taking AEDs. At this clinic visit, caregivers were asked to
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complete a Background Information Form and a seizure history form. During each follow-up visit, caregivers completed 1-10 questionnaires, and children aged 8 years and older completed 1-5 questionnaires (children ages 2-7 years did not complete questionnaires). Number of questionnaires completed by caregivers/children at each study visit was influenced by the number of questionnaires prearranged for that particular study visit (for example, the Parent Stigma Scale was only completed at 3 of 10 time points). At each assessment point, families were reimbursed for their time with a $20 gift certificate to a local store (e.g., Walmart/Target). All children were also given a small toy at each assessment point (less than $1.00 in value).

For the proposed study, the Background Information Form was collected at the initial time point (i.e. diagnosis) and the Parent Stigma Scale and Child Stigma Scale were collected approximately one month, one year, and two years post-diagnosis. During each study visit, trained research staff spoke with families during their regular epilepsy clinic appointments and visits were conducted in epilepsy examination rooms.

During each study visit, trained research staff explained the directions for each parent-reported questionnaire and allowed time for caregivers to ask questions or make comments. If child study participants were present, then trained research staff explained each self-reported questionnaire and allowed time for children to ask questions or make comments. Most children were able to answer question items independently; however if children requested assistance the research staff read items aloud. The research staff remained in the examination room until child participants had completed their questionnaires. Once participants completed questionnaires they were reimbursed and thanked for their time.
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Data that will be used for this study is currently located in locked cabinets and on password protected computers at a large, Midwestern children’s hospital. The datasets are coded to a number instead of identifying information. Access to this information has been granted by the principal investigator of the NIH-funded study and parental consent and child assent (when children were aged 8 years or older) for the use of this information for research purposes had been obtained prior to the collection of the data. Hospital Institutional Review Board (IRB) approval was granted prior to the collection of data for the larger study. Xavier University IRB approval will be acquired prior to conducting the proposed study.
Chapter IV: Proposed Analyses

The first aim in the study is to test the hypothesis that children with newly-diagnosed epilepsy and their caregivers will report decreasing amounts of epilepsy-related perceived stigma (i.e., scores on the Parent Stigma Scale and Child Stigma Scale) over time. To test this hypothesis, Hierarchical Linear Modeling (HLM) analyses will be conducted using Statistical Analysis Software (SAS) version 9.3 over three time points (baseline, one year post-diagnosis, and two years post-diagnosis). HLM is a statistical technique used to measure change over time and can be successfully used when there is missing data.

The second aim of the study is to test the hypothesis that children with seizures (i.e., one or more reported seizures between one and two years post-diagnosis) and their caregivers will experience higher epilepsy-related perceived stigma than children without seizures (i.e., no reported seizures between one and two years post-diagnosis) and their caregivers. To test this hypothesis, two one-tailed independent sample t-tests (parent and child) with an alpha level of p<.05 will be conducted with IBM Statistical Packages for Social Sciences (IBM SPSS) version 20 at two years post-diagnosis with seizures present (yes or no) as the independent variable and level of perceived stigma as the dependent variable.

The final aim of the study is to test the congruence between child and caregiver perception of epilepsy-related stigma (i.e., level of agreement between Parent Stigma Scale and Child Stigma Scale). Exploratory analyses via intraclass correlations will be
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certified with caregiver-child dyads using IBM SPSS version 20 at three time points
(baseline, one year post-diagnosis, and two years post-diagnosis). Intraclass correlations
(ICC) were chosen because it allows for the assessment of consistency of quantitative
measurements made by different observers measuring the same construct. The primary
difference between Pearson and intraclass correlation calculations is that the ICC uses
centered data that is scaled using a pooled mean and standard deviation, whereas in the
Pearson correlation, each variable is centered and scaled by its own mean and standard
deviation.
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References


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Table 1

**Participant Demographics and Medical Variables**

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Age (years), Mean ± SD, range</td>
<td>7.14 ± 2.87, 2.0 – 12.96 years</td>
</tr>
<tr>
<td>Child Sex</td>
<td>60.8% male</td>
</tr>
<tr>
<td>Child Race (%)</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>76.3</td>
</tr>
<tr>
<td>African-American</td>
<td>14.4</td>
</tr>
<tr>
<td>Other</td>
<td>3.1</td>
</tr>
<tr>
<td>More than one race</td>
<td>6.2</td>
</tr>
<tr>
<td>Seizure Type (%)</td>
<td></td>
</tr>
<tr>
<td>Localization-related</td>
<td>55.7</td>
</tr>
<tr>
<td>Generalized</td>
<td>24.7</td>
</tr>
<tr>
<td>Unclassified</td>
<td>19.6</td>
</tr>
<tr>
<td>Non-convulsive versus Convulsive Seizures (%)</td>
<td></td>
</tr>
<tr>
<td>Non-convulsive</td>
<td>32.0</td>
</tr>
<tr>
<td>Convulsive</td>
<td>68.0</td>
</tr>
<tr>
<td>Caregiver Age (years), Mean ± SD, range</td>
<td>35.63 ± 6.97, 21.40 – 60.02 years</td>
</tr>
<tr>
<td>Caregiver Race (%)</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>82.5</td>
</tr>
<tr>
<td>African-American</td>
<td>13.4</td>
</tr>
<tr>
<td>Other</td>
<td>2.1</td>
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<tr>
<td>More than one race</td>
<td>2.1</td>
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<tr>
<td>Questionnaires Completed By (%)</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>79.4</td>
</tr>
<tr>
<td>Father</td>
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<tr>
<td>Parent jointly</td>
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<tr>
<td>Other</td>
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<tr>
<td>Marital Status (%)</td>
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<tr>
<td>Married</td>
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<td>Divorced</td>
<td>9.3</td>
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<tr>
<td>Single</td>
<td>20.6</td>
</tr>
<tr>
<td>Other</td>
<td>5.1</td>
</tr>
<tr>
<td>Revised Duncan Score, Mean ± SD, range</td>
<td>42.81 ± 22.72, 15.00 – 97.16</td>
</tr>
</tbody>
</table>

Child characteristics reflect children of caregiver participants (ages 2-12, which include child study participants); SD, standard deviation; Revised Duncan Score is an occupation based measure of socioeconomic status (SES). Scores on the Revised Duncan range from 15-97, with higher scores equating to higher SES (Hauser, 1994).
Recruitment of Caregiver and Child Participants

Total N of eligible caregivers of children (ages 2-12) in larger study (N=110)

Total N of caregivers of children (ages 2-12) in larger study (N=105)

Total N of children ages 8 and older in larger study (N=46)

Total N of caregivers of children (ages 2-12) in current study (N=97)

Total N of children included in current study (N=39)
Recruitment of Caregiver Participants

Total N for larger study (N=110)

Total N recruited at diagnosis (N=105)

Total N not eligible for current study (N=8)

Did not return to clinic after diagnosis (N=2)

Terminated participation in study due to being seen in another clinic (N=1)

Baseline measures not completed/returned (N=5)

Total N included in current study (N=97)
Recruitment of Child Participants

Total N recruited at diagnosis (N=46)

Total N not eligible for current study (N=8)

Total N included in current study (N=39)

Did not return to clinic after diagnosis (N=2)

Terminated participation in study due to being seen in another clinic (N=1)

Did not complete measures due to caregiver or child request (N=2)

Difficulty comprehending measures (N=2)
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Appendix B

The Child Stigma Scale is protected by copyright so it is not reproduced in this document. The measure is available by contacting the developing author, Joan K. Austin, at joausti@iupui.edu.
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Appendix C

BACKGROUND INFORMATION

We would like to ask you a few questions about yourself. The questions ask about your educational background and current work. Please answer all of the questions as completely as possible. Please remember your answers will remain confidential.

1a. What is your gender? 1 = Female 2 = Male
1b. What is your marital status? 1 = single 2 = married 3 = divorced 4 = separated 5 = remarried 6 = widowed

1c. How are you related to the study participant?
I am his/her: 1 = mother 2 = stepmother 3 = grandmother 4 = aunt 5 = female legal guardian 6 = father 7 = stepfather 8 = grandfather 9 = uncle 10 = male legal guardian 11 = other (please describe)

2. What is your date of birth? _________/_________/_________

3. Education: How many years of schooling have you had? (Please circle one)
   1. Less than 7th grade
   2. Junior high school (9th grade)
   3. Partial high school (10th or 11th)
   4. High school graduate
   5. Trade school
   6. Partial college (at least one year of specialized training)
   7. College or university graduate (e.g. BA, BS)
   8. Graduate of professional degree

4a. What kind of work are you doing? (What is your occupation?)
(For example: Homemaker, retail sales, machinist, stock clerk, farmer, etc.)

4b. What are your most important activities or duties in your work?
(For example: selling merchandise, filing, supervising, assembly line, etc.)

4c. What kind of business or industry is this?
(For example: retail shoe store, automobile manufacturing, state labor department, etc.)
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4d. Is there another adult caregiver living in your home? (Please circle one)

   YES      NO      **IF NO**, please go to #5.

4e. **IF YES**, what is their relationship to you and/or the study participant? (Please circle one)

   (1) Husband/participant’s biological father
   (2) Wife/participant’s biological mother
   (3) Husband/participant’s stepfather
   (4) Wife/participant’s stepmother
   (5) My partner (boyfriend/girlfriend)
   (6) Participant’s grandmother
   (7) Participant’s grandfather
   (8) Other: ___________________________ (Please describe)

4f. Does this person share household expenses with you?

   YES      NO      **IF NO**, please go to #5.

   **IF YES**, please answer the following questions regarding this person.

4g. What is their date of birth? __________ / __________ / __________

4h. What kind of work are they doing? (What is their occupation?)

   (For example: Homemaker, retail sales, machinist, stock clerk, farmer, etc.)

4i. What are their most important activities or duties in their work?

   (For example: selling merchandise, filing, supervising, assembly line, etc.)

4j. What kind of business or industry is this?

   (For example: retail shoe store, automobile manufacturing, state labor department, etc.)

4k. Education: How many years of schooling have they had? (Please circle one)

   1. Less than 7th grade
   2. Junior high school (9th grade)
   3. Partial high school (10th or 11th)
   4. High school graduate
   5. Trade school
   6. Partial College (at least one year of specialized training)
   7. College or university graduate (e.g. BA, BS)
   8. Graduate of professional degree

5. Approximately what is your present annual family income? (CIRCLE ONE)

   1. under $ 4,000
   2. $ 4,000--$ 7,000
   3. $ 7,001--$10,000
   4. $10,001--$15,000
   5. $15,001--$20,000
   6. $20,001--$25,000
   7. $20,001--$30,000
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3. $7,001--$10,000
4. $10,001--$13,000
5. $13,001--$16,000
8. $30,001--$50,000
9. $50,001--$75,000
10. Over $75,000

6. Please list all of your children (including your child diagnosed with Epilepsy), starting with the oldest, and include birth date and sex. Also, please check if the child lives with you now.

<table>
<thead>
<tr>
<th>FIRST NAME (do not write last name)</th>
<th>BIRTH DATE (mo/day/year)</th>
<th>SEX (male/ female)</th>
<th>Living with you now (Yes or No)</th>
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7a. What is your race? ________

1 = White
2 = Black/African American
3 = Asian
4 = American Indian or Alaskan Native
5 = Native Hawaiian or other Pacific Islander
6 = Other: __________
7 = More than one race

7b. What is your ethnic background?

1 = Hispanic
2 = Non-Hispanic

8a. What is the race of your participant child? ________

1 = White
2 = Black/African American
3 = Asian
4 = American Indian or Alaskan Native
5 = Native Hawaiian or other Pacific Islander
6 = Other: __________
7 = More than one race

8b. What is the ethnic background of your participant child?

1 = Hispanic
2 = Non-Hispanic

Thank you for filling out this questionnaire.
Chapter V: Dissertation

Abstract

Children with epilepsy, approximately 326,000 children under the age of 15 in the United States, are at high risk for stigma (Begley et al., 2000; Jacoby & Austin, 2007). Long-term impacts of experiencing stigma include increased depression, poor self-concept, low overall quality of life, and low perception of ability to manage illness (Cheng-Fang et al., 2009; Dilorio et al., 2003; Funderburk et al., 2007; Leaffer et al., 2011; Weiss et al., 2006). Few studies have examined the perception of stigma (i.e., the internalized sense of shame that occurs from possessing a stigmatized attribute and the anticipation that others will discriminate against the stigmatized individual) among children with epilepsy (Jacoby & Austin, 2007). The aims of the current study are to: 1) examine the course of perceived epilepsy-related stigma among children and their caregivers 2) examine the influence of seizure absence/presence on children and caregivers’ perception of epilepsy-related stigma and 3) examine the congruence of child and caregiver perception of child epilepsy-related stigma. Ninety-seven caregivers and 39 children with epilepsy participated in this longitudinal study, with children’s ages ranging from 2 to 12, with a mean age of 7.14 ± 2.87. Using hierarchical linear modeling, both caregivers ($t_{176} = -2.57, p < .01$) and children with epilepsy ($t_{129} = -3.37, p < .01$) reported decreasing amounts of epilepsy-related stigma from diagnosis to two-years post-diagnosis. However, there were no differences in caregiver report ($t_{65} = .93, p = .32$) or child report ($t_{25} = - .89, p=.75$) of perceived stigma with children currently experiencing seizures when compared
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to children who have been seizure-free for the past year. Additionally, intraclass correlations revealed poor caregiver-child agreement of perceived epilepsy-related stigma at baseline ($r=-.01, p=.49$), one year following diagnosis ($r=-.06, p=.83$), and two years following diagnosis ($r=-0.49, p=.83$). Specifically, caregivers reported higher levels of stigma compared to children at baseline and two years post-diagnosis; whereas children reported higher levels of stigma compared to caregivers at one year post-diagnosis.

These findings suggest that children with epilepsy perceive decreasing amounts of epilepsy-related stigma over the first two years after diagnosis, but their level of stigma is not influenced by their seizure status. Finally, this study suggests that children and their caregivers have different opinions of the level of perceived stigma that children with epilepsy experience throughout the course of their first two years following diagnosis.
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Examine Perceived Stigma of Children with Newly-Diagnosed Epilepsy and Their Caregivers Over a Two-Year Period

Children with epilepsy, 326,000 children under the age of 15 in the United States, are at high risk for stigma (Begley et al., 2000; Jacoby & Austin, 2007). Long-term impacts of experiencing stigma include increased depression, poor self-concept, low overall quality of life, and low perception of ability to manage illness (Cheng-Fang et al., 2009; DiIorio et al., 2003; Funderburk, McCormick, & Austin, 2007; Leaffer et al., 2011; Weiss, Ramakrishna, & Somma, 2006). Few studies have examined the perception of stigma (i.e., the internalized sense of shame that occurs from possessing a stigmatized attribute and the anticipation that others will discriminate against the stigmatized individual) among children with epilepsy (Jacoby & Austin, 2007).

**Pediatric Epilepsy**

Epilepsy is a neurological disorder characterized by two or more unprovoked seizures (National Institute of Neurological Disorders and Stroke [NINDS], 2011). A seizure is a brief, excessive discharge of brain electrical activity which occurs when the brain continues to abnormally fire neurons instead of returning to homeostasis (Devinsky, 2008). Fifty to sixty percent of individuals with epilepsy are diagnosed prior to the age of 16 (Weaver, 2001) and the origin of epilepsy is often unknown (Hauser & Banerjee, 2008).

Epilepsy is classified by identifying the area of the brain affected by the abnormal electrical charges that cause the seizure. There are two broad classes of seizures: localization-related and generalized. Localization-related seizures, formally called partial seizures, refer to seizures that are focused in one hemisphere of the brain.
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(Commission on Classification and Terminology of the International League Against Epilepsy [ILAE], 2010). Generalized seizures originate in and engage both sides of the brain and include absence (staring spells), atonic, myoclonic, tonic, clonic, and tonic-clonic seizures (Williams, 2004).

Researchers have found that children with epilepsy often experience comorbid psychological conditions such as impaired academic performance, lower IQ scores (Salpekar & Dunn, 2007), learning disorders, attention deficit-hyperactivity disorder (Williams, 2004), depression, anxiety (Salpekar & Dunn, 2007), and behavioral problems (Funderburk et al., 2007).

Stigma

Current stigma research can trace its roots to Goffman’s (1963) conceptualization of stigma. According to Goffman (1963), stigma refers to an attribute that a person possesses which is deeply discrediting, represents undesired differentness, and reduces the stigmatized from a whole person to a tainted, discounted “other.” Researchers have noted that this definition of stigma has low clinical utility with current medical conditions and have suggested that stigma should refer to a social process, which can be experienced or anticipated, and consists of “exclusion, rejection, blame or devaluation that results from experience….or anticipation of an adverse social judgment” (Weiss et al., 2006). This judgment is based on a health problem or health-related condition and is medically unwarranted (Weiss et al., 2006).

Types of stigma. The concept of stigma can be divided into two parts: enacted and felt. Enacted stigma refers to the actual observed episodes of discrimination by others on the grounds of being socially flawed (Jacoby & Austin, 2007; Scambler, 2009).
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An example of enacted stigma occurs when a child with HIV is denied a position on the baseball team because his coach is afraid that the other teammates will somehow “catch HIV.” Felt or perceived stigma is the internalized sense of shame that occurs from possessing a stigmatized attribute and the anticipation that others will discriminate against the stigmatized individual (Jacoby & Austin, 2007; Scambler, 2009). An example of felt stigma may be a child with irritable bowel syndrome (IBS) hiding the illness from his/her classmates in fear of others thinking that he/she is somehow “disgusting.”

**Effects of stigma.** Stigma can impact individuals in a variety of ways. Researchers have demonstrated that individuals who experience stigma are at an increased risk for developing depression (Leaffer et al., 2011; Reisinger & Dilorio, 2009), heart disease and stroke (Major & O’Brien 2005), low self-concept (Funderburk et al., 2007), low self-esteem (Link, Struwning, Neese-Todd, Asmussen, & Phelan, 2001), low overall quality of life (Cheng-Fang et al., 2009; McLaughlin, Pachana, & McFarland, 2009), and lower confidence in their ability to manage their illness (Buston & Wood, 1999; Dilorio et al., 2003).

**Stigma measurement.** Stigma is difficult to measure due to the lack of a cohesive definition of what stigma actually encompasses. Stigma is defined as both something that happens to someone (enacted stigma) and fear or anticipation of something happening to someone (perceived stigma) because an individual possess a quality that is understood by society as undesirable (Goffman, 1963; Jacoby & Austin, 2007; Scambler, 2009). It can be studied using qualitative methods, such as interviews,
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focus groups, and participant observations, as well as quantitative methods, such as
questionnaires and stigma scales (van Brakel, 2005).

Research measuring health-related stigma in pediatric epilepsy is scarce.
Qualitative studies using focus groups have been conducted to examine the impact of
epilepsy on quality of life in children (Moffat, Dorris, Connor, & Espie, 2009). Disease
specific stigma scales have been developed to measure perceived stigma in both children
with epilepsy and their parents (Austin, MacLeod, Dunn, Shen, & Perkins, 2004). Also,
generic stigma scales have been used with children with chronic diseases to measure both
the child’s attitude toward his/her illness (Heimlich, Westbrook, Austin, Cramer, &
Devinsky, 2000) and the parent’s attitude towards the child’s illness (Austin et al., 2008).

An important issue regarding the measurement of stigma in children is whether
the respondent is the child or the child’s caregiver (e.g. parent-proxy measurement).
Parent-proxy measures are designed to be used as a substitute for child self-report
measures when children are too sick/ too weak to fill out questionnaires and/or when
children have limited cognitive or communication abilities and may not be able to
articulate their experiences (Ronen, Streiner, Rosenbaum, & the Canadian Pediatric
Epilepsy Network, 2003). Most children who are eight years of age or older are able to
accurately reflect on their experiences; however parents continue to complete parent-
proxy measures of their child’s emotional and psychosocial processes in both research
settings and clinical practice (Riley, 2004).

It is pertinent to examine level of congruence between child and parent reports of
perceived stigma because initiation and type of mental health treatment are often
contingent upon whether or not a caregiver believes that his/her child is experiencing
distress. When a child feels that he/she is being stigmatized but his/her parent disagrees, the child may not receive the necessary services to help ease the burden of feeling stigmatized. Also if a child does not feel like he/she is being stigmatized but his/her parent disagrees, then the child may receive unnecessary services.

Although studies have employed both child and parent reports of perceived stigma (Hirfanoglu et al., 2009; Ronen, Rosenbaum, Law, & Steiner, 1999), only one pediatric study has examined the congruence between the two reports (Lawrence, Rosenberg, Mason, & Fauerbach, 2011). Results from the study demonstrated high parent-child agreement when children reported low levels of perceived stigma and low parent-child agreement when children reported high levels of perceived stigma (Lawrence et al., 2011). These findings suggest that parents may be unaware of their children’s perception of health-related stigma; however, more research is needed to better understand the level of congruence between child and parent reports of perceived stigma.

A final measurement issue which needs to be addressed is the lack of longitudinal studies on health-related stigma with pediatric patients. Health-related stigma is typically studied using a cross-sectional sample of individuals with varying lengths of time since diagnosis (Austin et al., 2004; Heimlich et al., 2000; Lillis et al., 2010; Rao et al., 2009; van Brakel, 2005). Since no longitudinal studies have examined health-related stigma, it is difficult to understand the course of stigma following diagnosis.

**Stigma and Epilepsy**

Research has demonstrated that individuals with epilepsy may be at-risk for experiencing social difficulties, particularly in relation to stigma (Jacoby & Austin, 2007).
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**Stigma and adults.** Adults with epilepsy often rate stigma as one of the most unpleasant facets of having epilepsy (Fisher et al., 2000). Feelings of stigmatization may be influenced by geographic location and culture. In a relatively recent study conducted in Korea, 31% of individuals with epilepsy reported feeling stigmatized and 9% of individuals reported feeling highly stigmatized (Lee, Yoo, & Lee, 2005); whereas a similar study conducted in 15 different European countries revealed that 51% of individuals with epilepsy reported feeling stigmatized with 18% of these individuals feeling highly stigmatized (Baker, Brooks, Buck, & Jacoby, 2000). Analogous studies have not been conducted in the United States.

**Stigma and children.** Research with pediatric patients with epilepsy is scarce and therefore little is known about the influence of stigma on children with epilepsy (MacLeod & Austin, 2003). Past research has demonstrated long-term impacts of experiencing stigma such as, increased depression, poor self-concept, low overall quality of life, and low perception of ability to manage illness (Cheng-Fang et al., 2009; Dilorio et al., 2003; Funderburk et al., 2007; Leaffer et al., 2011; Weiss et al., 2006); however it is unknown if these results generalize to pediatric epilepsy. Stigma studies have examined what other people think about children with epilepsy, as well as what children with epilepsy think about themselves.

**Teacher, peer, and other perception.** Teacher, peer, and other perceptions of children with epilepsy are generally negative. One study found that nearly half of teachers interviewed believed that children with epilepsy differ from healthy children by their behavior, 26% believed that children with epilepsy are not able to achieve excellent school results, and 36% of the teachers were not confident in their approach to teach and
work with children with epilepsy (Prpic et al. 2003). With regards to peer perception, Austin et al. (2002) found that high school students believed that children with epilepsy were more likely to get picked on or bullied and Cheung and Wirrell (2006) found that youth rated epilepsy as having a significantly greater social impact than several other medical conditions and a similar social impact as HIV. Additionally, Gzirishvilia et al. (2013), found that while only 14 % of adults would object to their child going to school or playing with a person with epilepsy, 75 % of adults (and 82% of adults with a medical degree) would object to their child marrying a person with epilepsy.

**Child perception.** Studies have found mixed results in regards to children’s experiences of having epilepsy. One study found that most common concern with children with epilepsy was how they were perceived by others (Ronen et al., 1999). A similar study conducted with children with epilepsy and their parents revealed that children believed that they have experienced stigma associated with having epilepsy (Hirfanoglu et al., 2009). Interestingly, Westbrook et al. (1992) found that adolescents with epilepsy believed that having epilepsy did not influence their social lives (Westbrook et al., 1992).

**Adaption to diagnosis.** Past research has demonstrated that as children initially learn about their medical diagnosis, they go through a period of disbelief and shock (Clarke, Davies, Jenney, Glaser, & Eiser, 2005). As the family’s initial stress decreases and they become adjusted to the changes in routines (e.g., giving antiepileptic medications) and children obtain seizure control, the child may learn to integrate this information into his/her sense of self, then the illness becomes less of a “deeply
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discrediting attribute” (Goffman, 1963). Currently no research exists that examines the
subjective experience of children with epilepsy as they adapt to their diagnosis

Summary of existing literature and limitations

Few studies have examined the perception of stigma among children with
epilepsy and to date no studies have examined the course of perceived stigma after
diagnosis. Of the existing literature, researchers have used various stigma questionnaires
and have found mixed results regarding the extent to which children with epilepsy
anticipate being stigmatized (Hirfanoglu et al., 2009; Ronen et al., 1999; Westbrook et
al., 1992). One limitation of existing literature is that it is cross-sectional and includes
participants from a diverse range of time since diagnosis, and thus conclusions cannot be
drawn about the course of children’s perception of epilepsy-related stigma. Another
limitation is the absence of studies addressing parent-child agreement of perceived stigma
among children with epilepsy, and only one pediatric study examining this concept
outside of epilepsy (Lawrence et al., 2011). Finally it is unclear whether the presence or
absence of active seizures influences the perception of epilepsy-related stigma. While
several studies regarding stigma also measure seizure control/freedom, these studies have
not examined the impact of seizure status on perceived stigma (Fisher et al., 2000;
McLaughlin et al., 2009; Westbrook et al., 1992).

The aims of the study were to 1) examine the course of perceived epilepsy-related
stigma among children and their caregivers 2) examine the influence of seizure
absence/presence on children and caregivers’ perception of epilepsy-related stigma and 3)
conduct exploratory analyses to examine the congruence of child and caregiver
perception of child epilepsy-related stigma. Prior literature has demonstrated that
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children newly diagnosed with a chronic illness and their caregivers go through an initial period of disbelief and shock (Clarke et al., 2005) which likely increases the family’s perception of stigma associated with the child being diagnosed with a chronic illness. As the family’s initial stress level decreases and they become better adjusted to the diagnosis, the child may learn to integrate the diagnosis into his/her sense of self, thus allowing the illness to become less of a “deeply discrediting attribute” (Goffman, 1963). It was hypothesized that children and their caregivers would report decreasing amounts of epilepsy-related perceived stigma from baseline (within 1 month after diagnosis) to two years later and children with active seizures and their caregivers would experience higher epilepsy-related perceived stigma between one year and two years post-diagnosis than children without active seizures. Little is known about parent-child agreement of perceived stigma; therefore no formal hypotheses were made regarding level of congruence between caregiver and child reports of epilepsy-related perceived stigma.

Methods

Design

The current study is a longitudinal and included data collected over a two year period from caregivers of children with epilepsy (ages 2-12 years) and of children 8 years of age and older. All data were gathered between 2006 and 2011 and were part of a larger NIH-funded study examining adherence patterns and barriers to treatment of children newly-diagnosed with epilepsy.

Participants

Inclusion criteria for the larger study included 1) children with newly diagnosed epilepsy (i.e. recruited on the day of diagnosis), 2) children between the ages of 2-12
years, and 3) participants' ability to speak/write English for the completion of
questionnaires. Exclusion criteria for the larger study included 1) children with a
caregiver-reported developmental disorder and 2) children with a comorbid medical
diagnosis requiring daily medications. Additional inclusion criterion for the current study
was completion of the baseline Parent Stigma Scale (for caregivers) and Child Stigma
Scale (for children ages 8 years and older).

Measures

**Parent Stigma Scale.** The Parent Stigma Scale (Austin et al., 2004) is a five-
item instrument designed to measure caregivers' belief that their child is experiencing
stigma or will experience stigma from having epilepsy. Caregivers are instructed to
respond to five items on a five-point scale ranging from 1 (**strongly disagree**) to 5
(**strongly agree**). Item scores are summed and then averaged for a total stigma score
(range 1-5), with higher scores representing greater perceived epilepsy-related stigma.

Prior research has validated the use of the Parent Stigma Scale to evaluate
caregivers' perception of stigma associated with their child having epilepsy (Austin et al.,
2004). Internal reliability of the measure has been established, with reported coefficient
alphas ranging from 0.77 for the newly diagnosed sample and 0.79 for the chronic
sample. Corrected item-to-total correlations ranged from 0.50 to 0.64 in the newly
diagnosed sample and 0.52 to 0.70 in the chronic sample. Coefficient alpha for the
current study was 0.71 at baseline.

**Child Stigma Scale.** The Child Stigma Scale (Austin et al., 2004) is an eight-
item instrument designed to measure children's belief that they are experiencing or will
experience stigma from having epilepsy. Children are instructed to respond to the eight
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items on a five-point scale ranging from 1 (strongly disagree) to 5 (strongly agree). Item scores are summed and then averaged for a total stigma score (range 1-5), with higher scores representing greater perceived epilepsy-related stigma.

Prior research has validated the use of the Child Stigma Scale to evaluate children’s perception of stigma associated with having epilepsy (Austin et al., 2004). Reported coefficient alpha for a sample of children with chronic epilepsy was 0.81 and corrected item-to-total correlations ranged from 0.44 to 0.65. Coefficient alpha for the current study was 0.81 at baseline.

**Seizure Status.** Presence or absence of seizures was collected through medical chart review and parent report of the following questions 1) “how many seizures has your child had since their last clinic visit” and 2) “since your last clinic visit, have you noticed seizure activity or staring spells.” Children experiencing one or more seizures and/or staring spells were categorized as “seizures present,” while those with no reported staring spells or seizures were as “seizures absent.”

**Background Information Form.** The Background Information Form was completed by caregivers and contained information regarding family composition, child’s age, race, and sex, and caregivers’ age, race, sex, marital status, education, and occupation.

**Procedure**

The current study is a subset of a larger study. For the larger study, families meeting inclusion criteria were approached by trained research staff during their regular epilepsy clinic appointment (i.e. at diagnosis). A brief explanation was given to families that the purpose of the study was to gain an understanding of how children with epilepsy
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take their anti-epileptic drugs (AEDs) and the factors that interfere with taking AEDs. At this clinic visit, caregivers were asked to complete a Background Information Form and a seizure history form. During each follow-up visit, caregivers completed 1-10 questionnaires, and children aged 8 years and older completed 1-5 questionnaires (children ages 2-7 years did not complete questionnaires). Number of questionnaires completed by caregivers/children at each study visit was influenced by the number of questionnaires prearranged for that particular study visit (for example, the Parent Stigma Scale was only completed at 3 of 10 time points). At each assessment point, families were reimbursed for their time with a $20 gift certificate to a local store (e.g., Walmart/Target). All children were also given a small toy at each assessment point (less than $1.00 in value).

Data for the present study was obtained was from the Background Information Form, collected at the initial time point (i.e., diagnosis), and the Parent Stigma Scale and Child Stigma Scale, collected at approximately one month, one year, and two years post-diagnosis. Seizure status was determined by the presence/absence of a seizure between one and two years post-diagnosis (see Table 2 for schedule of measures).

During each study visit, trained research staff spoke with families during their regular epilepsy clinic appointments and visits were conducted in epilepsy examination rooms. Questionnaires were explained to families and time was allotted for them to ask questions or make comments. Caregivers and most children completed questionnaires independently; however if children requested assistance the research staff read items aloud in the presence of their caregivers. Once participants completed questionnaires they were reimbursed and thanked for their time.
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Data were kept confidential. Access to this information has been granted by the principal investigator of the larger study. Parental consent and child assent (when children were aged 8 years or older) for the use of this information for research purposes was acquired. Both medical center and university Institutional Review Boards (IRB) approvals were granted.

Results

The current study included data from 97 caregivers of children with newly-diagnosed epilepsy. Of the 110 eligible participants, 105 families agreed to participate in the larger study. However, data from 97 participants were included in the current study due to the following reasons: two did not return to clinic after diagnosis, one terminated participation in the study due to being seen in another clinic, and five participants had missing questionnaire data at baseline. Thus, the current participant cohort included data from 97 caregivers of children with newly-diagnosed epilepsy (mean age = 35.6 ± 6.9, 79.4 % mothers, and 82.5% Caucasian) (see Figure 1 for caregiver participant recruitment details). Their children had a mean age of 7.1 ± 2.8, were 60.8% male, and 76.3% Caucasian. See Table 1 for complete participant demographics and medical variables.

The current study also included data from 39 children, all of whom were newly-diagnosed with epilepsy and eight years of age and older. Of the 46 eligible child participants, data from only 39 child participants were included in the current study due to the following reasons: two did not return to clinic after diagnosis, two had caregivers who did not want their children to complete questionnaires, one did not complete questionnaires due to having a learning disability and being unable to comprehend the
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questionnaires, and one terminated participation from the study due to being seen in another clinic. Thus, the current child cohort included data of 39 children with newly-diagnosed epilepsy with a mean age of 9.95 ± 1.40, who were 51.3% male, and 79.5% Caucasian (see Figure 2 for child participant recruitment details).

Perceived Epilepsy-Related Stigma

Hierarchical Linear Modeling (HLM) analyses were conducted to test the first hypothesis that children with newly-diagnosed epilepsy and their caregivers would report decreasing epilepsy-related perceived stigma (i.e., scores on the Parent Stigma Scale and Child Stigma Scale) over time. The outcome variable of interest was epilepsy-related perceived stigma and time was the independent variable. Separate analyses were conducted for caregiver and child data using three time points (baseline, one year post-diagnosis, and two years post-diagnosis). As expected, both caregivers ($t_{1.26} = -2.57, p < .01$) and children ($t_{1.29} = -3.37, p < .01$) reported decreasing amounts of epilepsy-related stigma over time. Table 3 represents the final model statistics, while Figure 6 displays caregiver and child reports of epilepsy-related perceived-stigma over time.

Seizure Status

Two one-tailed independent sample t-tests (caregiver and child) were employed to test the second hypothesis that children with active seizures and their caregivers experience higher epilepsy-related perceived stigma between one year and two years post-diagnosis than children without active seizures. Results revealed no significant differences between children who experienced seizures versus those who did not on caregiver report ($t(65) = .93, p = .52$) or child report ($t(25) = -.89, p = .75$) of perceived stigma. Table 4 represents the final model statistics.
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Caregiver and Child Congruence

Exploratory analyses were conducted with the 37 caregiver-child dyads to examine the congruence between child and caregiver perception of epilepsy-related stigma (i.e., level of agreement between Parent Stigma Scale and Child Stigma Scale) via intraclass correlations. Results indicated poor caregiver-child agreement at baseline ($r = .01, p = .49$), one year following diagnosis ($r = -.06, p = .56$), and two years following diagnosis ($r = -.49, p = .83$). Specifically, caregivers reported higher levels of perceived stigma compared to children at baseline and two years after diagnosis and children reported higher levels of perceived stigma compared to caregivers at one year after diagnosis. Table 5 represents the final model statistics, while Figures 7, 8, and 9 displays the congruence between caregiver and child reports of epilepsy-related perceived stigma at baseline, one-year post-diagnosis, and two-years post-diagnosis.

Discussion

The current study is the first to use a longitudinal design to assess perceived-stigma among children with epilepsy and their caregivers. Cross-sectional research has concluded that children with epilepsy feel stigmatized by their peers and are worried about how others perceive them (Hirfanoglu et al., 2009; Ronen et al., 1999). It was hypothesized that children with newly-diagnosed epilepsy and their caregivers would report decreasing amounts of epilepsy-related perceived stigma from diagnosis to two-years later. Results confirmed this hypothesis for both caregiver and child reports. One perspective is that stigma decreases because caregivers tend to shift recreational activities from outside of the home to inside of the home which reduces the chance for children to experience discrimination and subsequent perceived stigma (Modi, 2009). Another
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perspective is that as children adapt and adjust to their epilepsy diagnosis, their perception of stigma decreases. As in any medical condition, when children with epilepsy and their caregivers initially learn about the epilepsy diagnosis they may go through a period of disbelief and shock (Clarke et al., 2005). As the family’s initial stress decreases and they become adjusted to the changes in routines (e.g., giving antiepileptic medications) and children obtain seizure control, the child with epilepsy learns to integrate this information into his/her sense of self, then the illness becomes less of a “deeply discrediting attribute” (Goffman, 1963). Currently no research exists that examines the subjective experience of children with epilepsy as they adapt to their diagnosis. Future research should examine this area, as well as investigate the relationship between child/caregiver adjustment to illness and level of perceived epilepsy-related stigma.

This study also examined the influence of seizure absence/presence on children and caregivers’ perception of epilepsy-related stigma. While several studies regarding stigma also measured seizure control/freedom, these studies have not examined the impact of seizure status on perceived stigma (Fisher et al., 2000; McLaughlin et al., 2009; Westbrook et al., 1992). Past research has demonstrated that psychosocial difficulties are more prominent among individuals who experience a higher frequency of seizures (Antonak and Livneh, 1992). It was hypothesized that children with active seizures and their caregivers would experience higher epilepsy-related perceived stigma between one year and two years post-diagnosis than children without active seizures. However, there were no differences in the amount of epilepsy-related stigma perceived by children with active seizures when compared to children who had been seizure-free between one year
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and two years post-diagnosis. The lack of difference may be due to the variability of seizure occurrence between one year and two years post-diagnosis. For example, a child who experienced one seizure at one year post-diagnosis would be classified as having an "active seizure status" but may not differ dramatically from children who did not experience active seizures; whereas a child who experienced thirty seizures between one and two years post-diagnosis may have a dramatically different experience. This also may mean that seizure control does not relate to perceived stigma. An additional problem may be an insufficient number of participants needed to detect a meaningful effect size. Power estimates calculated using G*Power 3.1.7 indicate a total sample size of N=174 needed to detect a medium effect size (d = .5). This number is substantially larger than the 67 total caregiver participants and 27 total child participants used in the current analysis. Future research should employ a larger sample size and further examine the relationship between frequency of seizures following one year post-diagnosis and impact of perceived epilepsy-related stigma.

Finally, exploratory analyses were conducted to examine the congruence of child and caregiver perception of child epilepsy-related stigma. Little is known about parent-child agreement of perceived stigma; therefore no formal hypotheses were made regarding level of congruence between caregiver and child reports of epilepsy-related perceived stigma. Results revealed poor parent-child agreement during all three assessment points. Specifically, caregivers reported higher levels of stigma compared to children at baseline and two years post-diagnosis; whereas children reported higher levels of stigma compared to caregivers at one year post-diagnosis. The absence of congruence may be accounted for by an insufficient number of participants needed to detect a
meaningful effect size. Power estimates calculated using G*Power 3.1.7 indicate a total sample size of N= 115 needed to detect a medium effect size (r = .3). This number is greater than the actual caregiver-child dyad sample size (i.e., 37 at baseline, 26 at one-year post-diagnosis, and 24 at two-years post-diagnosis. Although few studies have examined parent-child agreement of perceived stigma in pediatric diseases, an extensive amount of research has examined parent-child agreement in similar constructs, such as child Health-Related Quality of Life (HRQOL). Findings demonstrate that level of agreement between parent and child reports may be affected by the specific aspects of health that are being studied. For example, studies have demonstrated less parent-child agreement for internal, emotional and psychosocial factors when compared to concrete, external factors (Upton, Lawford, & Eiser, 2008; Verheyn et al., 2009). Since perceived stigma is an intrinsic factor, it is not surprising that level of congruence was low for caregiver and child reports of epilepsy-related stigma. It is important to understand the level of congruence between child and parent reports of perceived stigma since initiation and type of mental health treatment are often contingent upon whether or not a caregiver believes that his/her child is experiencing distress. When a child feels that he/she is being stigmatized but his/her parent disagrees, the child may not receive the necessary services to help ease the burden of feeling stigmatized. Additional research with a larger sample size is needed to better understand the relationship between child and caregiver report of perceived stigma; as well as the best manner in which to identity children who are experiencing a great deal of stigma and subsequent distress. It would be important to discover ways in which children could communicate their feelings of distress to their caregivers.
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Limitations

Although this study is the first longitudinal study to examine the level of perceived epilepsy-related stigma over time among children with epilepsy and their caregivers, limitations of the study were noted. The first limitation is the relatively small sample size of the child sample (n=39) who primarily represented children 8-12 years of age. This sample size is much smaller than other studies examining pediatric epilepsy and its relation to psychosocial aspects (Hirfanoglu et al., 2009; Westbrook et al., 1992). Continued exploration of perceived epilepsy-related stigma and its impact on children and their caregivers should be done with a larger sample and throughout the developmental period, including adolescence.

Second, a limitation of missing data should be noted. Although Hierarchical Linear Modeling was conducted which accounts for missing data, other statistical analyses (i.e., t-tests and intraclass correlations coefficients) were conducted which are unable to account for missing data. Thus, is important to note that missing data may have influenced the results. This is particularly true for the child sample, since this sample size began quite small (n=39) and decreased over the following two years (n=25).

Finally, this study did not examine the type of seizures experienced by child participants. Stigma literature suggests that individuals who experience more visible conditions are more likely to experience stigma than individuals who are able to easily conceal their illness (Jones et al., 1984; Quinn & Chaudoir, 2009). In the future it will be important for researchers to determine if level of perceived epilepsy-related stigma is related to type and/or frequency of seizure(s) so that interventions aimed at ameliorating
PERCEIVED STIGMA OF CHILDREN WITH EPILEPSY

the effects of stigma can be tailored to fit the specific needs of particular seizure types if indicated.

Strengths

This is the first study to examine the perception of epilepsy-related stigma over time. Past cross-sectional research has found conflicting results regarding the perception of epilepsy-related stigma among children with epilepsy, and while it is unknown, one reason for this discrepancy may be due to the variability of length of time since diagnosis (Fisher et al., 2000; McLaughlin et al., 2009; Westbrook et al., 1992). This study was the first attempt to understand the perception of epilepsy-related stigma that children with epilepsy experience at various times since diagnosis. Since the results of this study demonstrated that the perception of stigma is highest around diagnosis and then decreases over time, clinicians should intervene with stigma-reduction techniques, if indicated, shortly after children are diagnosed with epilepsy. While it is likely that stigma will decrease over time without mental health treatment, it is desirable to eliminate the influence of stigma shortly after it develops since experiencing stigma can lead to an increase risk of later developing depression (Leaffer et al., 2011; Reisinger & Dilorio, 2009), heart disease and stroke (Major & O’Brien 2005), low self-concept (Funderburk et al., 2007), low self-esteem (Link et al., 2001), low overall quality of life (Cheng-Fang et al., 2009; McLaughlin et al., 2009), and lower confidence in ability to manage illness (Buston & Wood, 1999; Dilorio et al., 2003).

To our knowledge, this is the first study to examine the influence of seizure activity status on the perception of epilepsy-related stigma among children with epilepsy. While several studies regarding stigma also measure seizure control/freedom, these
studies have not examined the impact of seizure status on perceived stigma (Fisher et al., 2000; McLaughlin et al., 2009; Westbrook et al., 1992). The current study demonstrated that children currently experiencing seizures have a similar perception of epilepsy-related stigma as those children who are not currently experiencing seizures.

Overall this study has several strengths and areas for future research. The current study examined the perception of epilepsy-related stigma among children with epilepsy over time. It is also the first study to examine the congruence between caregiver and child reports of epilepsy-related stigma, as well as the influence of seizure status on the perception of epilepsy-related stigma. Similar research should be conducted in the future with a larger child sample and a larger caregiver-child dyad sample.
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References


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Table 1

Participant Demographics and Medical Variables

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Age (years), Mean ± SD, range</strong></td>
</tr>
<tr>
<td><strong>Child Sex</strong></td>
</tr>
<tr>
<td><strong>Child Race (%)</strong></td>
</tr>
<tr>
<td>Caucasian</td>
</tr>
<tr>
<td>African-American</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>More than one race</td>
</tr>
<tr>
<td><strong>Seizure Type (%)</strong></td>
</tr>
<tr>
<td>Localization-related</td>
</tr>
<tr>
<td>Generalized</td>
</tr>
<tr>
<td>Unclassified</td>
</tr>
<tr>
<td><strong>Non-convulsive versus Convulsive Seizures (%)</strong></td>
</tr>
<tr>
<td>Non-convulsive</td>
</tr>
<tr>
<td>Convulsive</td>
</tr>
<tr>
<td><strong>Caregiver Age (years), Mean ± SD, range</strong></td>
</tr>
<tr>
<td><strong>Caregiver Race (%)</strong></td>
</tr>
<tr>
<td>Caucasian</td>
</tr>
<tr>
<td>African-American</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>More than one race</td>
</tr>
<tr>
<td><strong>Questionnaires Completed By (%)</strong></td>
</tr>
<tr>
<td>Mother</td>
</tr>
<tr>
<td>Father</td>
</tr>
<tr>
<td>Parent jointly</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td><strong>Marital Status (%)</strong></td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Divorced</td>
</tr>
<tr>
<td>Single</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td><strong>Revised Duncan Score, Mean ± SD, range</strong></td>
</tr>
</tbody>
</table>

Child characteristics reflect children of caregiver participants (ages 2-12, which include child study participants); SD, standard deviation; Revised Duncan Score is an occupation based measure of socioeconomic status (SES). Scores on the Revised Duncan range from 15-97, with higher scores equating to higher SES (Hauser, 1994).
Table 2

Schedule of Measures

<table>
<thead>
<tr>
<th>Time</th>
<th>Background Information Form</th>
<th>Parent Stigma Scale</th>
<th>Child Stigma Scale</th>
<th>Seizure Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One Month Post-Diagnosis</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>One Year Post-Diagnosis</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Two Years Post-Diagnosis</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

The Background Information was collected at diagnosis. The Parent Stigma Scale and Child Stigma Scale were collected one month, one year, and two years post-diagnosis. Seizure Status was determined by the presence/absence of a seizure between one year and two years post-diagnosis.
Table 3

*Descriptive Statistics for Caregiver and Child Reports of Epilepsy-Related Perceived Stigma at Baseline, One-Year Post-Diagnosis, and Two-Years Post-Diagnosis*

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td>2.15</td>
<td>0.76</td>
<td>97</td>
</tr>
<tr>
<td>Child</td>
<td>2.11</td>
<td>0.87</td>
<td>39</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td>2.0</td>
<td>0.73</td>
<td>69</td>
</tr>
<tr>
<td>Child</td>
<td>1.63</td>
<td>0.69</td>
<td>29</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td>1.88</td>
<td>0.70</td>
<td>67</td>
</tr>
<tr>
<td>Child</td>
<td>1.61</td>
<td>0.55</td>
<td>25</td>
</tr>
</tbody>
</table>
**PERCEIVED STIGMA OF CHILDREN WITH EPILEPSY**

Table 4

*Descriptive Statistics for Children With Active Seizures and Children Without Active Seizures Between One-Year and Two-Years Post-Diagnosis*

<table>
<thead>
<tr>
<th>Seizures</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present</td>
<td>2.05</td>
<td>0.74</td>
<td>12</td>
</tr>
<tr>
<td>Absent</td>
<td>1.84</td>
<td>0.69</td>
<td>55</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Seizures</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present</td>
<td>1.38</td>
<td>0.65</td>
<td>3</td>
</tr>
<tr>
<td>Absent</td>
<td>1.68</td>
<td>0.56</td>
<td>24</td>
</tr>
</tbody>
</table>
**Table 5**

*Descriptive Statistics for Caregiver-Child Dyads at Baseline, One-Year Post-Diagnosis, and Two-Years Post-Diagnosis*

<table>
<thead>
<tr>
<th></th>
<th><strong>Mean</strong></th>
<th><strong>SD</strong></th>
<th><strong>Range</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Baseline (N=37)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>2.35</td>
<td>0.73</td>
<td>1.0 – 4.0</td>
</tr>
<tr>
<td>Child</td>
<td>2.11</td>
<td>0.89</td>
<td>1.0 – 5.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>Mean</strong></th>
<th><strong>SD</strong></th>
<th><strong>Range</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>One-Year Post-Diagnosis (N=26)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>1.61</td>
<td>0.72</td>
<td>1.0 – 3.5</td>
</tr>
<tr>
<td>Child</td>
<td>1.95</td>
<td>0.80</td>
<td>1.0 – 4.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>Mean</strong></th>
<th><strong>SD</strong></th>
<th><strong>Range</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Two-Years Post-Diagnosis (N=24)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>1.75</td>
<td>0.61</td>
<td>1.0 – 2.8</td>
</tr>
<tr>
<td>Child</td>
<td>1.59</td>
<td>0.56</td>
<td>1.0 – 3.25</td>
</tr>
</tbody>
</table>
Recruitment for Caregiver Participants

Total N eligible for larger study (N=110)

Total N in larger study recruited at diagnosis (N=105)

Total N not eligible for the current study (N=8)

Total N included in the current study (N=97)

- 2 did not return to clinic after diagnosis
- 1 terminated participation in study due to being seen in another clinic
- 5 did not complete baseline measures
Recruitment of Child Participants

- 2 did not return to clinic after diagnosis
- 1 terminated participation in study due to being seen in another clinic
- 2 did not complete Child Stigma Scale per caregiver or child request
- 2 had difficulty comprehending Child Stigma Scale
Caregiver Participant Missing Data

Missing Data at One Year Post-Diagnosis (N=28)
- 11 did not return for their regular clinic appointment
- 5 withdrew from the study due to unknown reasons
- 1 un-enrolled from the study due to being seen in another clinic
- 3 moved and were no longer participants in the study
- 3 missed this clinic appointment due to clinical progress
- 2 did not complete/return the questionnaires for unknown reasons
- 3 missed the clinic appointment for unknown reasons

Missing Data at Two Years Post-Diagnosis (N=30)
- 15 did not return for their regular clinic appointment
- 7 withdrew from the study due to unknown reasons
- 4 moved and were no longer participants in the study
- 2 participants were caregivers of children weaning off of their medication
- 1 did not complete/return the questionnaire for unknown reasons
- 1 un-enrolled from the study due to being seen in another clinic
Child Participant Missing Data

Total N at Baseline = 39

Total N at One Year Post-Diagnosis = 29

Total N at Two Years Post-Diagnosis = 25

Missing Data at One Year Post-Diagnosis (N=10)
- 5 did not return for their regular clinic appointment
- 2 withdrew from the study due to unknown reasons
- 1 un-enrolled from the study due to being seen in another clinic
- 1 did not complete/return the questionnaire for unknown reasons
- 1 missed the clinic appointment for unknown reasons

Missing Data at Two Years Post-Diagnosis (N=14)
- 8 did not return for their regular clinic appointment
- 3 withdrew from the study due to unknown reasons
- 1 un-enrolled from the study due to being seen in another clinic
- 1 did not complete/return the questionnaire for unknown reasons
- 1 was weaning off of medication
Caregiver-Child Dyad Participant Missing Data

Missing Data at One Year Post-Diagnosis (N=11)
- 5 did not return for their regular clinic appointment
- 2 withdrew from the study due to unknown reasons
- 2 did not complete/return the questionnaires for unknown reasons
- 1 missed the clinic appointment for unknown reasons
- 1 un-enrolled due to being seen in another clinic

Missing Data at Two Years Post-Diagnosis (N=13)
- 7 did not return for their regular clinic appointment
- 4 withdrew from the study due to unknown reasons
- 1 un-enrolled due to being seen in another clinic
- 1 child was weaning off medication
Figure 6

*Observed and model-based caregiver and child stigma scores over a 2-year period*
Congruence between caregiver and child reports of epilepsy-related perceived stigma at baseline

**Assessment Point: 0**

- **Parent Stigma Scale**
  - 4.00
  - 3.50
  - 3.00
  - 2.50
  - 2.00
  - 1.50
  - 1.00

- **Child Stigma Scale**
  - 1.00
  - 2.00
  - 3.00
  - 4.00
  - 5.00
CONGRUENCE BETWEEN CAREGIVER AND CHILD REPORTS OF EPILEPSY-RELATED PERCEIVED STIGMA AT ONE-YEAR POST-DIAGNOSIS
Figure 9

*Congruence between caregiver and child reports of epilepsy-related perceived stigma at two-years post-diagnosis*
April 19, 2012

Jennifer L. Daniel
1929 Dallas Ave.
Cincinnati, OH 45239

Dear Ms. Daniel:

Re: Protocol #163. Examining Perceived Stigma of Children with Newly-diagnosed Epilepsy and Their Caregivers over a Two-Year Period

The IRB has reviewed the materials regarding your study, referenced above, and has determined that it meets the criteria for the Exempt from Review category under Federal Regulation 45CFR46. Your protocol is approved as exempt research, and therefore requires no further oversight by the IRB.

If you wish to modify your study, including the addition of data collection sites, it will be necessary to obtain IRB approval prior to implementing the modification. If any adverse events occur, please notify the IRB immediately.

Please contact our office if you have any questions. We wish you success with your project.

Sincerely,

[Signature]

Moodle E. Mullins, Jr., Ph.D.
Chair, Institutional Review Board
Xavier University

e: Janet Schultz, Advisor
PERCEIVED STIGMA OF CHILDREN WITH EPILEPSY

Appendix B

The Social Stigma Scale is protected by copyright so it is not reproduced in this document. The measure is available by contacting the developing author, Joan K. Austin, at joaustii@iupui.edu.
The Child Stigma Scale is protected by copyright so it is not reproduced in this document. The measure is available by contacting the developing author, Joan K. Austin, at joausti@iupui.edu.
PERCEIVED STIGMA OF CHILDREN WITH EPILEPSY

Appendix D

BACKGROUND INFORMATION

We would like to ask you a few questions about yourself. The questions ask about your educational background and current work. Please answer all of the questions as completely as possible. Please remember your answers will remain confidential.

1a. What is your gender? _______ 1b. What is your marital status? _______
   1 = Female 1 = single 4 = separated
   2 = Male 2 = married 5 = remarried
   3 = divorced

1c. How are you related to the study participant?
   I am his/her: 1 = mother 6 = father
   2 = stepmother 7 = stepfather
   3 = grandmother 8 = grandfather
   4 = aunt 9 = uncle
   5 = female legal guardian 10 = male legal guardian
   11 = other (please describe) ____________________________

2. What is your date of birth? _______ / _______ / _______

3. Education: How many years of schooling have you had? (Please circle one)
   1. Less than 7th grade
   2. Junior high school (9th grade)
   3. Partial high school (10th or 11th)
   4. High school graduate
   5. Trade school
   6. Partial College (at least one year of specialized training)
   7. College or university graduate (e.g. BA, BS)
   8. Graduate of professional degree

4a. What kind of work are you doing? (What is your occupation?)
   (For example: Homemaker, retail sales, machinist, stock clerk, farmer, etc.)

4b. What are your most important activities or duties in your work?
   (For example: selling merchandise, filing, supervising, assembly line, etc.)

4c. What kind of business or industry is this?
   (For example: retail shoe store, automobile manufacturing, state labor department, etc.)

4d. _______ Is the
   YES    NO    IF NO, please go to #5.
4e. **IF YES,** what is their relationship to you and/or the study participant? (Please circle one)

(1) Husband/participant’s biological father  
(2) Wife/participant’s biological mother  
(3) Husband/participant’s stepfather  
(4) Wife/participant’s stepmother  
(5) My partner (boyfriend/girlfriend)  
(6) Participant’s grandmother  
(7) Participant’s grandfather  
(8) Other: _______________________________ (Please describe)

4f. Does this person share household expenses with you?  

**YES**  
**NO**  
**IF NO,** please go to #5.

4g. **IF YES,** please answer the following questions regarding this person.

What is their date of birth?  

_________/_________/_________

4h. What kind of work are they doing? (What is their occupation?)

(For example: Homemaker, retail sales, machinist, stock clerk, farmer, etc.)

4i. What are their most important activities or duties in their work?

(For example: selling merchandise, filing, supervising, assembly line, etc.)

4j. What kind of business or industry is this?

(For example: retail shoe store, automobile manufacturing, state labor department, etc.)

4k. Education: How many years of schooling have they had? (Please circle one)

1. Less than 7th grade  
2. Junior high school (9th grade)  
3. Partial high school (10th or 11th)  
4. High school graduate  
5. Trade school  
6. Partial College (at least one year of specialized training)  
7. College or university graduate (e.g. BA, BS)  
8. Graduate of professional degree

5. Approximately what is your present annual family income? (CIRCLE ONE)

1. under $ 4,000  
2. $ 4,000-- $ 7,000  
3. $ 7,001-- $10,000  
4. $10,001-- $13,000  
5. $13,001-- $16,000  
6. $16,001--$20,000  
7. $20,001--$30,000  
8. $30,001--$50,000  
9. $50,001--$75,000  
10. Over $ 75,000
6. Please list all of your children (including your child diagnosed with Epilepsy), starting with the oldest, and include birth date and sex. Also, please check if the child lives with you now.

<table>
<thead>
<tr>
<th>FIRST NAME (do not write last name)</th>
<th>BIRTH DATE (mo/day/year)</th>
<th>SEX (male/female)</th>
<th>Living with you now (Yes or No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7a. What is your race? __________    7b. What is your ethnic background?

1 = White
2 = Black/African American
3 = Asian
4 = American Indian or Alaskan Native
5 = Native Hawaiian or other Pacific Islander
6 = Other: __________________     1 = Hispanic
2 = Non-Hispanic

8a. What is the race of your participant child? __________     8b. What is the ethnic background of your participant child?

1 = White
2 = Black/African American
3 = Asian
4 = American Indian or Alaskan Native
5 = Native Hawaiian or other Pacific Islander
6 = Other: __________________     1 = Hispanic
2 = Non-Hispanic

7 = More than one race

Thank you for filling out this questionnaire.
PERCEIVED STIGMA OF CHILDREN WITH EPILEPSY

Examining Perceived Stigma of Children with Newly-Diagnosed Epilepsy and Their Caregivers Over a Two-Year Period

Problem

Children with epilepsy, approximately 326,000 children under the age of 15 in the United States, are at high risk for stigma (Begley et al., 2000; Jacoby & Austin, 2007). Long-term impacts of experiencing stigma include increased depression, poor self-concept, low overall quality of life, and low perception of ability to manage illness (Cheng-Fang et al., 2009; DiLorio et al., 2003; Funderburk et al., 2007; Leaffler et al., 2011; Weiss et al., 2006). Few studies have examined the perception of stigma (i.e., the internalized sense of shame that occurs from possessing a stigmatized attribute and the anticipation that others will discriminate against the stigmatized individual) among children with epilepsy (Jacoby & Austin, 2007), and to date, no studies have examined changes in the perception of epilepsy-related stigma over time.

Not every child with epilepsy will experience epilepsy-related stigma and it is unclear why some children feel stigmatized while other children do not. While several studies regarding stigma also measured seizure control/freedom, these studies have not examined the impact of seizure status on perceived stigma (Fisher et al., 2000; McLaughlin et al., 2009; Westbrook et al., 1992).

Finally, when conducting research with children, it is important to address level of congruence between child and parent reports. Initiation and type of mental health treatment are often contingent upon whether or not a parent believes his/her child is experiencing distress. Little is known about parent-child agreement of perceived stigma and to date no studies have examined this construct in pediatric epilepsy.
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Method

Archival data from 97 caregivers of children with epilepsy and 39 children with epilepsy were used to determine if the perception of epilepsy-related stigma changes over a two-year period following diagnosis, if seizure status has an impact on the amount of perceived epilepsy-related stigma among children and their caregivers, and the extent to which children with epilepsy and their caregivers agree about the amount of epilepsy-related stigma that children perceive. Data were used from the Background Information Form, Parent Stigma Scale, Child Stigma Scale, and self-reported seizure status between one and two years post-diagnosis.

It was hypothesized that children with epilepsy and their caregivers would report a decreasing amount of perceived epilepsy-related stigma between diagnosis and two years later. It was also hypothesized that children currently experiencing seizures would report a higher perception of epilepsy-related stigma when compared to children who were not currently experiencing active seizures. Finally, exploratory analyses were conducted to examine the congruence between caregiver and child reports of child perception of epilepsy-related stigma.

Findings

Hierarchical Linear Modeling (HLM) analyses were conducted to test the hypothesis that children with newly-diagnosed epilepsy and their caregivers would report decreasing amounts of epilepsy-related perceived stigma (i.e., scores on the Parent Stigma Scale and Child Stigma Scale) over time. The outcome variable of interest was epilepsy-related perceived stigma and time was the independent variable. Separate analyses were conducted for caregiver and child data using three time points (baseline,
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one year post-diagnosis, and two years post-diagnosis. As expected, both caregivers 
\( t_{1.76} = -2.57, p < .01 \) and children \( t_{1.29} = -3.37, p < .01 \) reported decreasing amounts of 
epilepsy-related stigma over time.

Two one-tailed independent sample t-tests (caregiver and child) were employed to 
test the second hypothesis that children with active seizures and their caregivers 
experience higher epilepsy-related perceived stigma between one year and two years 
post-diagnosis than children without active seizures. Results revealed no significant 
differences in caregiver report \( t(65) = .93, p = .32 \) or child report \( t(25) = -.89, p = .75 \) 
of perceived stigma with children currently experiencing seizures when compared to 
children who have been seizure-free for the past year.

Exploratory analyses were conducted with the 37 caregiver-child dyads to 
examine the congruence between child and caregiver perception of epilepsy-related 
stigma (i.e., level of agreement between Parent Stigma Scale and Child Stigma Scale) via 
intraclass correlations. Results indicated poor caregiver-child agreement at baseline 
\( r = .01, p = .49 \), one year following diagnosis \( r = -.06, p = .56 \), and two years following 
diagnosis \( r = -.49, p = .83 \). Specifically, parents reported higher levels of stigma 
compared to children at baseline and two years post-diagnosis; whereas children reported 
higher levels of stigma compared to caregivers at one year post-diagnosis.

Implications

The current study is the first to use a longitudinal design to assess perceived-
stigma among children with epilepsy and their caregivers. Results demonstrated a 
decrease in epilepsy-related stigma for both caregiver and child reports. One perspective 
is that as children become better adjusted to their diagnosis their perception of stigma
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decreases. Currently no research exists that examines the subjective experience of children with epilepsy as they become accustomed to their diagnosis. Future research should examine this area, as well as investigate the relationship between child/caregiver acclimation to illness and level of perceived epilepsy-related stigma.

The study is also the first study to examine the influence of seizure status on the perception of epilepsy-related stigma among children with epilepsy. While several studies regarding stigma also measure seizure control/freedom, these studies have not examined the impact of seizure status on perceived stigma (Fisher et al., 2000; McLaughlin et al., 2009; Westbrook et al., 1992). The current study demonstrated that children currently experiencing seizures have a similar perception of epilepsy-related stigma as those children who are not currently experiencing stigma.

Finally, this study is that it is the first study to examine the congruence between child and caregiver reports of the perception of epilepsy-related stigma. Initiation and type of mental health treatment are often contingent upon whether or not caregivers believe that their children are experiencing distress. Results from this study demonstrate poor caregiver-child congruence of perceived epilepsy-related stigma. While this is the first study to examine this construct, the number of caregiver-child dyads in this study were low (n=37) and thus future studies should replicate this study using a larger sample size.