

Parent-Teacher Communication Concerning Epilepsy:

To Disclose or Not to Disclose

by

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ABSTRACT

Epilepsy is a neurological condition that sometimes pervades all domains of an affected child's life. At school, three specific threats to the wellbeing of children with epilepsy exist: (1) seizure-related injuries, (2) academic problems, and (3) stigmatization. Unfortunately, educators frequently fail to take into account educationally-relevant epilepsy information when making important decisions. One possible explanation for this is that parents are not sharing such information with teachers. This study surveyed 16 parents of children with epilepsy in order to determine the rate at which they disclosed the epilepsy diagnoses to their children's teachers, as well as the difficulty with which they made the decision to disclose or withhold such information. In addition, the relationships between such disclosure and parent-participants' perceptions of the risks of epilepsy-related injuries, academic struggles, and stigmatization at school were examined. Results indicate that all participants disclosed their children's epilepsy diagnoses to their children's teachers, and most (69%) reported that making this decision was "very easy." There were no statistically significant associations between disclosure and any of three parental perception variables (perceptions of the threats of injury, academic problems, and stigmatization at school). Limitations, implications, and directions for future research are discussed.

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Chapter 1

BACKGROUND INFORMATION AND LITERATURE REVIEW

This chapter outlines the rationale for an investigation of parent-teacher communication concerning childhood epilepsy. It commences with a brief preamble featuring medically-related information about childhood epilepsy intended to familiarize the non-specialist with the topic. This is followed by the literature related to parental perceptions of three classes of adversity that threaten children with epilepsy at school: safety hazards, academic difficulties, and stigmatization, and by a review of the current literature regarding parent-teacher communication. The first chapter concludes with a set of research hypotheses.

Background Information

The following comprises a brief overview of epilepsy, a neurological condition characterized by recurrent seizures, or periods of irregular electrical brain activity, that affects approximately 10 children per 1,000 in the United States (Hauser & Hersdorffer, 1990). This exposition is intended to provide readers with a foundation for understanding school-related issues associated with childhood epilepsy, including safety risks, academic difficulties, and stigmatization. Understanding how individual children with epilepsy are impacted in school can be accomplished by considering three varying facets of the condition: seizures, epilepsy diagnosis, and treatment.

Seizures

Seizures that occur in children with epilepsy involve, in general, disturbances in the communication among neurons. Normal electrical impulses

between these cells and tissues stimulate the processes of perceptions, voluntary movements and actions, thoughts, and autonomic functions. The excessively rapid and deviant neuronal firing that typically takes place during a seizure, then, disrupts any or all of these processes, resulting in a variety of physiological and perceptual phenomena. Some individuals with well-controlled epilepsy rarely experience seizures, whereas others with poorly controlled epilepsy might experience hundreds per day.

The specific presentation and duration of symptoms during a seizure depends upon both severity of neuronal disturbance and the part of the brain associated with the irregular activity (Centers for Disease Control and Prevention [CDC], 2009). Due to the advantages of locating physiological points of origin and symptoms of seizures in children with epilepsy, physicians have identified over 30 different varieties of seizures. To simplify the classification system, specific seizure types are usually grouped into two super-ordinate categories based upon the areas affected within the brain: primary generalized seizures and partial seizures. Seizures subsumed within these two groups are further distinguished according to their observable symptoms (U.S. Department of Health and Human Services, 2004), allowing witnesses without access to neurological imaging equipment to distinguish among children's seizures.

Primary generalized seizures, characterized by irregular neuronal activity that occurs on both sides of the brain, occur in four main types that vary in the conspicuousness of symptoms: tonic-clonic, atonic, myoclonic, and absence seizures (Epilepsy Foundation, n.d.; U.S. Department of Health and Human

Services, 2004). A child undergoing a generalized tonic-clonic seizure, the first type of generalized seizure, also called a grand mal, displays up to a few minutes of extremely noticeable and often distressing symptoms, including crying out, falling down, stiffening or jerking of the arms and legs, and losing consciousness (CDC, 2009). The second and third types of primary generalized seizures, generalized atonic and myoclonic seizures, are also obvious, as they present as falls due to sudden losses of muscle tone or jerks of the arms, legs, or upper body, respectively (U.S. Department of Health and Human Services, 2004). Conversely, absence seizures, or petit mals, are less readily observed; they manifest as 2- to 15-second episodes of stares, eyelid flutters, or automatic movements.

In contrast to generalized seizures onset, partial seizures, also referred to as focal seizures, originate within a specific brain area. That is, generalized seizures concern the brain in general, whereas partial seizures concern part of the brain only. Although experiences among children with partial seizures differ according to the site of neuronal disturbance, onlookers can identify partial seizures as simple or complex by observing whether or not a child remains conscious. A child undergoing a simple partial seizure maintains consciousness while experiencing unreal or unexplainable sensory or emotional phenomena. During a complex partial seizure, consciousness is either altered, leaving a child in a dreamlike state, or lost altogether. Children having a complex partial seizure may exhibit repetitive behaviors called automatisms ranging from simple movements (e.g., lip smacking) to multi-step actions (e.g., drying a single dish multiple times; U.S. Department of Health and Human Services, 2004). In some

instances, partial seizures spread outside the area of the brain in which they began; they are termed secondary generalized seizures (CDC, 2009). In varying degrees and depending upon seizure type, the symptoms of episodes belonging to either main category (i.e., primary generalized or partial seizures) can frighten teachers, produce injury, limit learning, and provoke stigmatization.

Epilepsy Diagnoses

Epilepsy is a term encompassing hundreds of different seizure-related disorders, each exemplified by a unique presentation of symptoms. Concerning the conglomeration of separate epilepsy syndromes that must be organized into a hierarchical classification system, the National Institute of Neurological Disorders and Stroke (U.S. Department of Health and Human Services, 2004) advises individuals with epilepsy and their caregivers against making medical decisions based upon categorical generalizations. The prognoses, symptoms, and appropriate treatments for individuals with epilepsy are syndrome-specific, NINDS cautions, and thus patients and caregivers should consult with physicians regarding the implications of their particular diagnoses before making condition-related decisions. In order to make comparisons among epilepsy-related factors in scientific investigations, however, researchers often group epilepsy syndromes into categories based upon etiology. In this regard, epilepsy can be simply characterized as: (a) symptomatic, in which seizures occur as a result of preexisting damage or disease within the brain; (b) idiopathic, in which seizures occur due to genetic factors; or (c) cryptogenic, in which the cause of seizures is unknown (CDC, 2009). As with seizure type, specific epilepsy diagnoses can be

related to the extent of condition-related problems experienced by children at school.

Treatment

For children with epilepsy, treatment is aimed at minimizing the occurrence of seizures. In almost all cases, physicians attempt this feat by means of prescribing medications known as antiepileptic drugs (AEDs). AED types, of which there are more than 20, and optimum dosages differ across patients and depend upon characteristics such as age and seizure type and frequency. Upon initiating treatment regimens, physicians may need to adjust dosages or prescribe different AEDs to maximize seizure control and minimize medication side effects. Possible side effects of AEDs include fatigue, dizziness, weight gain, depression, psychosis, and allergic reactions (U.S. Department of Health and Human Services, 2004). Thus, newly treated patients must be closely monitored. Monotherapy, treatment involving only one AED, inhibits seizures for some people with epilepsy. In some cases, patients must take multiple AEDs to achieve seizure control (U.S. Department of Health and Human Services). Concerning the relative proportions of mono- and polytherapeutic medication regimens among children with epilepsy in school, one study of 50 children with epilepsy revealed that 64% of participants followed a monotherapeutic regimen and 28% followed a polytherapeutic regimen. The remaining participants were not currently prescribed with AEDs (Wodrich, Kaplan, & Deering, 2006). Because medication regimens and the side effects that accompany them vary, there is no universal

“medication plan” about which educators can learn so as to allow them to consistently identify side effects and ensure treatment adherence.

Unfortunately, approximately 1/3 of patients who undergo AED treatment continue to experience seizures (CDC, 2009). In these cases, patients may approach less common treatment strategies. These include surgical removal of compromised brain tissue from which seizures originate; implantation of a vagus nerve stimulator, a device that sends electrical impulses to the vagus nerve in the neck; and restriction of carbohydrates with a ketogenic diet (CDC, 2009). Concerning both AED and alternative epilepsy treatments, effectiveness and side effects prove relevant when considering the safety, academic performance, and social standing of children with epilepsy at school.

Literature Review

For children with epilepsy, the potential consequences of their condition extend far beyond the physiological symptoms experienced during seizures. That is, their epilepsy typically permeates many aspects of their everyday lives and jeopardizing their physical, social, and emotional welfare. At school, a central domain in most children’s lives, the degree to which epilepsy-related struggles endanger the wellbeing of children with the condition likely varies, both in actuality and as perceived by their parents. In order to examine these threats, the host of potential adversities that children with epilepsy face at school can be subdivided into three categories: safety hazards, stigma, and educational performance deficits. These three categories, which are the basis of this study, are reviewed below.

Safety Hazards Faced by Children with Epilepsy at School

Epilepsy is believed to be associated with a risk of injury to those with the condition, as concluded by Wirrell (2006) subsequent to a review of the substantial body of literature regarding epilepsy and injury. Intuitively, injuries incurred at school by children with epilepsy might be caused by the symptoms of seizures themselves. For example, a child might hit his or her head on a hard surface or break a bone as a result of muscle spasms or falls during a generalized tonic-clonic, atonic, or myoclonic seizure. Moreover, the loss of awareness that occurs during a seizure might cause injury by inhibiting a child's perception of and response to dangerous cues in the school environment (e.g., walking into a door or tripping down a flight of stairs). Supporting these speculations are results of several investigations that have discovered head injuries (Buck, Baker, Jacoby, Smith, & Chadwick, 1997; van den Broek & Beghi, 2004; Wirrell et al., 1996), broken bones (Buck et al., 1997; van den Broek & Beghi, 2004) and dental injuries (Buck et al., 1997) to be common among seizure-related injuries. In response to these possibilities, the Center for Disease Control and Prevention (2009) suggests safety precautions for persons with epilepsy such as preventing contact with hazards, removing hard or sharp objects from the vicinity, and placing something soft under the person's head during seizures.

Although seizures undoubtedly have the potential to cause serious injury at school, research concerning the severity and frequency with which children with epilepsy actually sustain seizure-related injuries has yielded inconsistent results. As indicated by the results of the few published investigations of children

with epilepsy, the proportion of child-participants who incurred at least one seizure-related injury ranged from 12.6% to 27% (Appleton, 2002; Kirsch & Wirrell, 2001; Wirrell, Camfield, Camfield, Dooley, & Gordon, 1996).

Regarding the central concern of this study, which deals with school, knowledge of the rate of seizure-related injury is virtually nonexistent. Of three studies involving children with epilepsy above, only one provided data concerning injuries sustained at school. As reported by their parents, 6 of 198 newly diagnosed and untreated patient-participants between the ages of 4 and 16 years old were injured due to a seizure that occurred at school (Appleton et al., 2002). Because of characteristics of the sample of child-participants, this finding may not represent the rate of occurrence for seizure-related injuries at school across all children with epilepsy. The children who participated were newly diagnosed epilepsy patients who, presumably, had experienced fewer seizures than many children who had been diagnosed with epilepsy for longer periods of time. Moreover, research suggests that children with epilepsy who do not suffer from cognitive deficits are less likely to be injured than their mentally handicapped counterparts (Kirsch & Wirrell, 2001), and no physical or severe cognitive disabilities existed among participants in the study conducted by Appleton et al. Participants with attention-deficit hyperactivity disorder were permitted to participate, however, and this group demonstrated more seizure-related injuries, which supports related findings of greater incidence of injury among this population (Kirsch & Wirrell, 2001). In addition to comorbid cognitive impairments and attention-deficit hyperactivity disorder, greater seizure

frequency, multiple adverse reactions to AED's, and generalized myoclonic and tonic-clonic seizure types have been identified as potential risk factors for sustaining injuries during seizures (Appleton et al., 2002).

It is easy to imagine that parents might worry about their child becoming injured as a result of a seizure. However, research concerning the prevalence and magnitude of parental apprehension about epilepsy-induced injury is limited. In one investigation conducted by Hoar, Mann, and Dunn (2000), 102 parents of children with epilepsy completed a questionnaire intended to measure their perceptions of their children's quality of life. Three of the 30 epilepsy-related items were associated with concerns about epilepsy-induced risks to safety. When parents were asked about how often they worried about the risk of epilepsy-related injury to their child, 82% of parents reported "sometimes" or "often." When asked how frequently they worried that their child would stop breathing due to epilepsy, 36% of parents reported "sometimes" or "often." Alarming, 49% of parents expressed some stress concerning the risk of brain damage or death to their children as a result of epilepsy. These results suggest that many parents are notably worried about epilepsy-related threats to their children's safety, at least some of the time. One might also expect parents of children who exhibit elevated injury risk factors (e.g., tonic-clonic seizures, high seizure frequencies, and cognitive impairments) to worry even more.

Risks to Academic Success

Among the adverse outcomes associated with childhood epilepsy are academic difficulties. Compared to their non-epileptic peers, children with

epilepsy are more likely to receive special education services (Berg et al., 2005). Regarding the proportion of children with epilepsy who require such services, the results of one investigation conducted by Wodrich and colleagues found that 56% of child-participants with epilepsy were enrolled in special education programs. This greater risk was especially true for those children with symptomatic epilepsy, who were more than twice as likely to receive special education services than their idiopathic counterparts. Psychometrically-based studies have also found children with epilepsy to be more likely to meet criteria for learning disability diagnosis (Fastenau, Shen, Dunn, & Austin, 2008), and score lower on IQ tests (Bailet & Turk, 2000) than controls (see Williams 2004 for a review)

Several characteristics of epilepsy and its treatments may account for the higher prevalence of academic deficits among children with epilepsy. Dizziness and confusion that can ensue from seizures in what is known as a postictal period may temporarily inhibit learning and performance in the classroom (Aldenkamp et al., 2001). Moreover, many children with epilepsy follow an anti-epileptic medication regime. While anti-epileptic drugs (AED) help to reduce the occurrence of seizures, they can have side-effects such as dizziness, headaches, shaking, reduced motor speed, sleepiness, mood changes, and memory and concentration problems. These adverse medication effects could impede learning and schoolwork completion (Baker et al., 2008; Boerr, Mula, & Sander, 2007). Absenteeism may exacerbate school-related tribulations, as childhood epilepsy sufferers tend to miss more days of school (Aguiar et al., 2007; Baker et al.,

2007). Thus, there is a real basis for concern about the academic outcomes of children with epilepsy.

Regarding this array of academic issues, limited evidence has been collected about parental concern. Available data, however, suggest that children with epilepsy and their parents do worry about academic deficits following epilepsy diagnosis. For example, in an international survey measuring self-reported experiences of 212 children with epilepsy and their parents, Baker and colleagues (2008) discovered that apprehension regarding schoolwork completion and educational future ranked among the highest concerns for 47% of caregivers, with 44% believing that problems could be at least partially attributed to medication side effects. Along with parents whose children experience AED side effects, parents of children with academic risk factors (e.g., a diagnosis of symptomatic epilepsy) might worry more about educational morbidity than parents whose sons and daughters are free of these factors.

Risks of Stigmatization

Epilepsy and its accompanying seizures are often dramatic and anxiety-producing. Thus, they place children at risk for enduring social stigma, which has been defined as discrimination, disapproval, rejection, and exclusion from others (Austin, Schafer, & Deering, 2002; Boer et al., 2008). Historically, stigmatization of people with epilepsy was exemplified by false beliefs (e.g., that the condition signified demonic possession) and discriminatory policies (e.g., prohibition against marriage to prevent producing offspring with the condition). Although such extreme examples of epilepsy-related stigma are no longer common in most

developed countries, social ostracism associated with epilepsy and seizures persists. For people with epilepsy, this stigmatization can manifest as exclusion from social activities by those who fear and misunderstand seizures, or from professional and educational activities by those who associate the condition with physical or mental deficiencies (Boer et al., 2008). Consequently, according to the report from the first national conference on public health and epilepsy sponsored by the CDC, the American Epilepsy Society, the National Association of Epilepsy Centers, and the Epilepsy Foundation, reducing the scope and severity of the stigmatization faced by those with epilepsy represents one of six top priorities for improving the lives of those with epilepsy (CDC, 2009).

The largest scale investigation of stigma concerning epilepsy, a survey of 19,441 adolescents in the general population across the United States, sheds light on the characterization of epilepsy-related stigma directed towards children with the condition (Austin et al., 2002). Over one-half of respondents responded “Yes” or “Not sure” in response to the item, “Do you think kids with epilepsy are likely to get picked on or bullied more than other kids?” (p. 372). Along with bullying, children with epilepsy were perceived to enjoy less popularity due to their condition. Moreover, only 31% of adolescent-participants indicated that they would be willing to date a person with epilepsy. Along with negative social perceptions, adolescent-participants demonstrated false beliefs about epilepsy, with 19% endorsing the condition as a “form of mental illness” (p. 371; 54% of respondents indicated that they did not now if epilepsy signified mental illness).

Such misconceptions undoubtedly contribute to peer ostracism of children with epilepsy.

Classmates are not the only possible source of stigmatization against children with epilepsy; teachers, inadvertently or otherwise, may also harbor negative attitudes concerning students with the condition. For example, Bishop and Boag (2006) investigated this possibility with a nationally representative survey of 512 U.S. teachers' knowledge about and attitudes towards people with epilepsy. Regarding teacher-participants' attitudes, although educator-participants' responses indicated attitudes that were generally positive and supportive of equal rights for children with epilepsy, results did indicate that some teachers maintain unfavorable perceptions of such students. For example, participants indicated only slight endorsement of the item, "The responsibility for educating children with epilepsy rests with the community" (p. 401; $M = 1.27$ on a Likert-type scale from -3, "I disagree very much," to 3, "I agree very much."). Moreover, approximately 10% of teachers did not think that children with epilepsy should be able to receive special education services under the Individuals with Disabilities Education Act (IDEA). Presently, no evidence exists concerning the extent to which teachers' attitudes and beliefs concerning epilepsy affect their teaching practices when working with students with the condition.

Regarding the present study's key concern, parental perceptions, several investigations have measured presumptions of stigma. Most multiple-item measures of stigma perceived by people with epilepsy and their parents have been restricted to those perceptions of teenagers and adults (Austin, MacLeod, Dunn,

Shen, & Perkins, 2004). In one investigation of perceived stigma among 64 adolescents with epilepsy, approximately one third of participants thought that their condition induced discrimination from others; parental perceptions were not measured (Westbrook, Bauman, & Shinnar, 1992). Use of the most recently developed and extensively validated perceived stigma scale with substantial sample sizes of both children with epilepsy and their parents (173 children with epilepsy and 224 of their parents) has indicated that parents are slightly more worried about stigmatization than the children themselves. Neither group, however, perceived high absolute levels of stigma (on a Likert-type scale from 1, “strongly disagree [that stigma is present],” to 5 “strongly agree [that stigma is present],” $M = 2.58$ for parents, and $M = 2.24$ for children; pp. 478-479). Items on this scale referred to how much children with epilepsy and their parents feared discrimination from an undifferentiated, general population. Consequently, items referencing stigma expressed by school personnel, who can exert control over students’ daily routines and educational experiences, may elicit different responses.

Educators’ Knowledge Concerning Epilepsy

Among the factors that might influence parental disclosure (the topic of this study) are educators’ knowledge and their classroom management of epilepsy. This section reviews the literature related to teachers’ awareness and practices concerning epilepsy. First, the benefits of providing educationally relevant information about students’ epilepsy to teachers are highlighted. Next, the current lack of consideration given to educationally relevant information

concerning epilepsy by educators is discussed. Finally, parental withholding of epilepsy information is implicated as one potential cause of educators' failure to attend to such information.

For children experiencing epilepsy-related school problems, educators' knowledge concerning their students' medical status can impact the accuracy of educational decisions. This was found in one analogue investigation conducted by Wodrich (2005). This study found that when provided with no information concerning a hypothetical student's epilepsy diagnosis, teachers were likely to misattribute classroom difficulties characterized by typical condition-related declines in academic performance to causes such as laziness, low intellectual ability, or learning disability. For a youngster with epilepsy, unfortunately, this mistake could lead to inappropriate special education placement that fails to take health-related issues into account. On the other hand, teachers who received facts about the hypothetical student's medical condition, which consisted of both an epilepsy diagnosis and an enumeration of common epilepsy-related classroom problems, were more likely to cite impairment associated with student's health as the probable cause of academic decline. Concerning students with epilepsy, teachers with access to more medical information were able to make more accurate appraisals concerning the medical roots of their students' academic struggles.

Educators' awareness of the medical origins of scholastic impairments has been linked to more effective classroom interventions. In another analogue experiment concerning diabetes, second chronic health condition related to

adverse academic outcomes, Cunningham and Wodrich (2006) asked teacher-participants to suggest educational modifications for a hypothetical student presenting with typical disease-related classroom difficulties. Those teachers who read more information about the student's diabetes recommended significantly more appropriate and disease-specific accommodations. In addition to the intuitive benefits of maximizing knowledge of academically-relevant information among educators, these results support researchers' arguments that educational teams who correctly identify students' epilepsy-specific academic problems can plan targeted classroom interventions and prevent disadvantageous educational outcomes such as erroneous special education placements and unnecessary transfers to self-contained special education classrooms (Wodrich & Cunningham, 2008).

There are also reasons that parents might be concerned about school. Unfortunately, investigations into teachers' and school psychologists' explanation of academic deficits among children with epilepsy indicate that many educational decisions are made without taking condition-related factors into account. An examination of school records, including psychological reports and individual education plans, of 30 students with epilepsy revealed many academically-important aspects of the students' conditions were ignored by educators (Wodrich, Kaplan, & Deering, 2006). Observable characteristics of seizures and AED regimens failed to appear in approximately half and two-thirds of the children's school records, respectively. Completely absent from all of the children's records were mention of postictal impairments and AED side effects.

These findings indicate that educators of children with epilepsy sometimes fail to attend to the condition in a manner that would promote effective targeted interventions.

Parental Withholding of Information as a Potential Hindrance to Teachers' Awareness: Rationale for the Proposed Investigation

Suboptimal school practices and lack of parental disclosure, the topic of this study, might be linked. In other words, one possible explanation for the dearth of attention given to epilepsy-related factors in students' school records may be that members of the educational teams are never made aware of such information. Until they recognize the existence of children's epilepsy conditions and associated classroom manifestations, these teams are at-risk for making misattributions that may adversely affect children's educations and prevent the formation of successful interventions. Teachers have identified receiving health information from parents, who possess individualized information about their children's seizures and their treatment, as a preferred way to learn about students' epilepsy (Bishop & Boag, 2006). Consequently, parental disclosure of epilepsy information (e.g., disclosing epilepsy diagnosis and symptoms with teachers) represents one method by which educators' responses to academic difficulties might be improved.

In order to determine the necessity for interventions aimed at increasing parent-teacher communication regarding epilepsy, along with the methods by which such interventions should be employed, one must assess both the rates and predictors of parental disclosure. However, no published documentation presently

exists regarding methods for measuring parent-teacher communication about epilepsy. Nonetheless, limited data concerning epilepsy-related disclosure in general can be used to hypothesize about the crucial topic of such disclosure to schools. For example, a survey of adolescents, but not their parents, indicated that approximately one-half kept their epilepsy a secret at least some of the time (Westbrook et al., 1992). Similarly, in one international survey of 512 parents and caregivers of children and adolescents with epilepsy, 23% of respondents admitted to keeping their child's epilepsy a secret. Most (62%) who endorsed this practice indicated that the withholding was due to fear of differential treatment from others (Baker et al., 2007). In both studies, teachers unfortunately were not singled out as individuals from whom information was withheld. In other words, teachers were not the focus of these studies. Moreover, these studies are either dated or did not use domestic samples.

Beyond the dearth of information about rate of disclosure is a similar deficiency regarding why parents may or not disclose information (i.e., an epilepsy diagnosis). Nonetheless, available knowledge about the experiences of children with epilepsy and their families allows for speculations concerning parents' rationales for disclosure and nondisclosure to teachers. When deciding how much epilepsy-related information to provide to teachers, parents may rely upon their perceptions of how such disclosures would affect their children's wellbeing at school. School-specific rationales for withholding children's epilepsy diagnoses, such as ignorance of available teaching modifications or belief that epilepsy is a purely medical phenomenon may also exist. Moreover, some parents

(e.g., those with children experiencing frequent generalized tonic-clonic seizures) may be more apt to disclose their child's diagnosis for safety reasons. Crucially, however, inferences about parents' disclosure and their perceptions of their children's safety, risks of educational morbidity, and vulnerable to stigma are merely speculative at present.

Thus, due to the host of school-associated difficulties related to childhood epilepsy and the importance of increased parent-school communication, the present study aimed to determine how often and how readily parents disclose epilepsy information to teachers. Given the research reviewed above, this study examined whether parental perceptions of safety risks, classroom performance deficits, and stigma predict parental disclosing of epilepsy information to teachers. The following results were predicted:

1. The proportion of parents who report sharing their child's epilepsy diagnosis with teachers will be less than 1.
2. The degree of difficulty parents associate with deciding whether or not to share their child's epilepsy diagnosis with teachers will differ for parents who decide to disclose and withhold such information.
3. Disclosing epilepsy diagnoses with teachers will occur more frequently among parents more concerned that their child's epilepsy carries accidental injury risks.
4. Disclosing epilepsy diagnoses with teachers will occur more frequently among parents who are more concerned that their child's epilepsy carries academic risks.

5. Disclosing epilepsy diagnoses with teachers will occur less frequently among parents who are more concerned that their child's epilepsy carries stigma among classmates.

METHOD

Participants

Participants were 16 mothers (or female caregivers) of children with epilepsy. Their ages ranged from 32 to 58 years ($M = 41.38$; $SD = 7.09$). Concerning ethnicity, 81% ($n = 13$) of participants identified themselves as White, and 19% ($n = 3$) identified themselves as Hispanic. Participants' children with epilepsy were from 5 to 17 years of age ($M = 11.44$; $SD = 4.15$) and enrolled in kindergarten through grade 12 ($M = 6$; $SD = 4.12$). Males comprised 56% ($n = 9$) of participants' children with epilepsy, and females comprised 44% ($n = 7$). Public schools were attended by 88% of respondents' children ($n = 14$), and charter schools by 12% ($n = 2$). Parents identified their children as White (75%; $n = 12$), Hispanic (19%; $n = 3$) or Other (6%; $n = 1$).

Instrument: *Epilepsy Parental Concern and Disclosure Indicator (EPDCI)*

A questionnaire was constructed and administered to participants using an online survey program in order to gather data regarding both their concerns about epilepsy-related threats to their children at school and their disclosure of information concerning their children's epilepsy to teachers, as well as demographic information.

Parental Perceptions of Epilepsy at School. This study concerns three predictor variables related to three aspects of parental perception: perception regarding their child's risk of seizure-related injury, perception regarding their child's risk of epilepsy-related academic problems, and perception regarding their

child's risk of encountering social stigmatization among classmates. To measure these three variables (as well as two others, discussed below), the *Epilepsy Parental Concern and Disclosure Indicator (EPCDI)* was developed. Three Likert-type items were used to measure each of the three Parental Perception of Epilepsy at School variables (i.e., parental perception of seizure-related injury risk, parental perception of academic risk, and parental perception of the risk of social stigmatization from classmates).

The first step in developing the Parental Perception of Epilepsy at School items on the *EPCDI* was defining the predictor variables. The first predictor variable (perception regarding the risk of seizure-related injury) is defined as the degree to which parent-participants worry that their children will be hurt at school as a result of an accident that occurs because of a seizure. The second predictor variable (perception regarding the risk of epilepsy-related academic problems) is defined as the degree to which parent-participants worry about their children experiencing epilepsy-related academic deficits in the form of compromised grades, standardized test scores, or classroom participation. The third predictor variable (perception regarding the risk of encountering social stigmatization among classmates) is defined as the degree to which parent-participants worry about their children being excluded from activities or treated differently by their peers as a result of having epilepsy.

Three items corresponding to each definition were then written (see Appendix). Each item is accompanied by ordinal response options ranging from 1, indicating no parental worry about the epilepsy-related risk, to 5, indicating

extreme parental worry about the epilepsy-related risk. Next, an expert focus group comprised of neurologists and educational psychologists reviewed items for representativeness and readability. Lastly, items deemed unsuitable were revised.

Upon confirmation of suitable inter-correlation among the three items used to assess each of the Parental Perception variables, sums of scores on each of these were used. No grand total score was used.

Parental Disclosure of Epilepsy to School (dependent variable). The dependent variable in this study, Parental Disclosure of Epilepsy to School, is parents' disclosure of their child's epilepsy diagnosis (to the immediate teacher). This variable is defined as whether or not parents exchanged written or spoken words with a teacher that specifically referred to any aspect of their children's epilepsy diagnosis, including the occurrence of seizures, related medical appointments, and prescribed medications. Parental Disclosure of Epilepsy to School was measured with a single, dichotomous item on the *EPCDI* (see Appendix). After the item was written, the expert focus group reviewed it for representativeness and readability; it was revised per focus group suggestions.

Difficulty of Parental Disclosure. The degree to which parents experienced difficulty while deciding whether or not to disclose their child's epilepsy diagnosis to teachers is termed Difficulty of Parental Disclosure. This variable was assessed with one, Likert-type item, with possible scores ranging from 1, indicating extreme ease with the decision, to 5, indicating extreme difficulty with the decision (see Appendix). The expert focus group reviewed the

item for representativeness and readability; it was revised per focus group suggestions.

Procedure

Prior to recruiting participants, the study was approved by the Institutional Review Board at Arizona State University. Representatives from the Epilepsy Foundation of Arizona also approved of the study and agreed to collaborate in participant recruitment.

The focus of this study was parents of children who have epilepsy. Participants were considered eligible to participate if they met the following inclusionary criteria: (a) custodial parent or guardian of a child who has been diagnosed with epilepsy by a physician, (b) parent or guardian of a child with epilepsy who is enrolled in a public or charter school, grades kindergarten through 12, (c) legal adult with an age of at least 18 years, (d) fluent English speaker and reader. Parents or legal guardians of children with epilepsy will be excluded from this study if their child's epilepsy diagnosis is determined within one month prior to recruitment.

Parents were recruited from two sources: The Epilepsy Foundation of Arizona's electronic mailing list and attendees of the organization's 9th Annual Epilepsy Walk. The Epilepsy Foundation of Arizona's electronic mailing list was used to recruit potential parent-participants in two ways. First, an appointed representative of the Epilepsy Foundation of Arizona sent an electronic mail message to all 117 parent-members of the organization's mailing list. Second, a volunteer-request posting was included in the organization's monthly

eNewsletter, subscribed to by over 1,000 readers. Both the message and the posting contained a participant-recruitment letter (see Appendix) detailing the purpose of the study and instructions for completing the survey. Participants were assured their participation was voluntary and anonymous, and that they could stop the questionnaire at anytime by exiting the website. The letter also included a notification informing them that their completion of the questionnaire would be considered their consent to participate. At the bottom of the message was a hyperlink that participants clicked to complete the survey and demographic questionnaire. Finally, researchers disseminated participant-recruitment letters and cards with the website address for the survey at the Epilepsy Foundation of Arizona's 9th Annual Epilepsy Walk.

Because of the nature of participant recruitment, it was not possible to determine how many potential participants received and read the recruitment letter. Consequently, the proportion of recruited parents who decide to enroll in the study (i.e., the response rate) could not be identified.

Chapter 3

RESULTS

Item-level analysis

In order to evaluate the internal consistency among the items used to measure the Parental Perception of Epilepsy at School variables (perception regarding the risk of seizure-related injury, perception regarding the risk of epilepsy-related academic problems, and perception regarding the risk of encountering social stigmatization), or the assumption that each of the nine items used to measure Parental Perception of Epilepsy at School are related to the other two items corresponding to the same variables (perception regarding the risk of seizure-related injury, perception regarding the risk of epilepsy-related academic problems, and perception regarding the risk of encountering social stigmatization), item inter-correlations were computed among participants' responses to each set of three items (see Table 1).

Descriptive Statistics

Medians, Means and standard deviations for both item scores and summed scores on the Parental Perception of Epilepsy at School variables (perception regarding the risk of seizure-related injury, perception regarding the risk of epilepsy-related academic problems, and perception regarding the risk of encountering social stigmatization) are displayed in Tables 2 and 3. Concerning parents' reported concerns about the risk of their children with epilepsy suffering seizure-related injuries at school, the mean composite score was 3.38, which fell between "moderately" and "significantly" worried. The mean score for the second

Parental Perception of Epilepsy at School variable, parental concern about the threat of academic performance problems, the composite-score mean was 4.02, which fell between “significantly” and “very significantly” worried. Lastly, the mean composite score for parental concern about the threat of stigmatization, 3.24, fell between “significantly” and “very significantly” worried.

Hypothesis 1: Parental Disclosure of Epilepsy to Teachers

Pertaining to Hypothesis 1, that the proportion of parents who chose to disclose their children’s epilepsy to teachers would be less than 1, all parents reported that they had notified their children’s teachers about his or her epilepsy diagnosis.

Hypothesis 2: Relationship between Parental Disclosure of Epilepsy to School and Difficulty of Parental Disclosure

Hypothesis 2 was that there would be discrepancies in the levels of difficulty parents experience while deciding to disclose between those parents who report disclosure and those parents who report non-disclosure. Because all parent-participants in this study reported disclosure, this hypothesis could not be evaluated.

Hypotheses 3 through 5: Relationship between Parental Perceptions of Epilepsy at School and Parental Disclosure of Epilepsy to School

Hypotheses 3 through 5 regarded the relationships between Parental Disclosure of Epilepsy to Teachers and each of the three Parental Perception of Epilepsy at School variables. Because all parents reported disclosure, these relationships could not be evaluated. Consequently, supplemental evaluations of

the relationships between Difficulty of Disclosure and each of the three Parental Perception of Epilepsy at School variables were conducted through the computation of Spearman correlation coefficients. In other words, it was thought that non-disclosure concerned the same variable as degree of difficulty deciding to disclose (the former dichotomous, the latter ordinal). The familywise error rate (alpha level) was set at .05. Bonferroni corrections were used to control for the risk of Type 1 error across multiple analyses.

Concerning the relationship between Difficulty of Disclosure and parental concern about the risk of seizure-related injury (modified Hypothesis 3), a scatterplot was first examined (see Figure 1). No linear relationship between the two variables could be observed. The distribution of Difficulty of Disclosure appeared negatively skewed and bimodal, while that of parental concern about the risk of seizure-related injury approximated normality. Next, a Spearman correlation coefficient of -0.15 ($p = .59$; $n = 16$) was computed. This relationship was not statistically significant.

The next analyses conducted pertained to the relationship between Difficulty of Disclosure and parental concern about epilepsy-induced academic problems (modified Hypothesis 4). A scatterplot between these variables was scrutinized (see Figure 2). In general, a positive linear relationship between the two variables was observed, except for two outlying data points that had Difficulty of Disclosure scores of 1 and parental concern about epilepsy-induced academic problems scores of 14 and 15. Parental concern about academic problems appeared to be negatively skewed. The Spearman correlation coefficient

between these two variables was 0.38 ($p = 0.16$, $n = 15$). The relationship was not statistically significant.

Regarding the relationship between Difficulty of Disclosure and parental concern about the risk of stigmatization (modified Hypothesis 5), the scatterplot between these variables was scrutinized (see Figure 3). The distribution for parental concern about the risk of stigmatization appeared to be negatively skewed. Due to the propensity of Difficulty of Disclosure scores of 1, no linear relationship between the two variables could be observed. The Spearman correlation coefficient between these two variables was 0.31 ($p = 0.26$, $n = 15$). The relationship was not statistically significant.

Hypotheses 3 through 5: Secondary Analysis

In order to determine whether the proportion of multivariate variability of the three Parental Perception of Epilepsy at School summed scores accounted for by Parental Disclosure of Epilepsy to School (Wilks's Lambda) was statistically significant, as well as establish the linear combination of the three Parental Perception of Epilepsy at School scores that best-discriminated between those parents who reported disclosure of epilepsy to schools and those who did not, a multivariate analysis of variance and subsequent discriminate analysis were planned, contingent upon adequate sample and effect sizes (as determined by an empirical power analysis subsequent to data collection). As this analysis depended upon variation in Parental Disclosure of Epilepsy to Teachers, it was not possible.

Chapter 4

DISCUSSION

Contrary to Hypothesis 1, which predicts that not all parents will disclose of epilepsy-related information to their child's teacher, no parent-participants in this study reported withholding their children's epilepsy diagnoses. It was quite unanticipated that every one of the 16 parents in this study reported telling their child's school about the presence of epilepsy. This finding juxtaposes that of Westbrook and colleagues' (1992) investigation in which nearly one-fourth of parent-participants reported keeping secret their children's epilepsy diagnosis. Nonetheless, it is critical to note that participants in Westbrook and colleagues' study did not specify from whom they withheld their children's diagnoses. Thus, it is possible that parents in that study actually did disclose to teachers (i.e., that they withheld the diagnoses from someone else). If such was the case, one might conjecture that in that study, like in this one, there was a high occurrence of parent-teacher disclosure of epilepsy diagnoses.

Alternatively, because of this study's small sample size and its recruiting methods, parents who had withheld information from school may not have been included. This might be so because this study's results were based on the responses of only 16 parents, all of whom either belonged to a well-established, epilepsy-specific organization (i.e., a local chapter of The Epilepsy Foundation) or attended a local philanthropic event aimed at helping those with epilepsy (i.e., The Epilepsy Walk). Thus, this sample comprises only parents who both involve themselves with epilepsy-related funding and care enough about epilepsy-related

research to invest their time as participants. A greater percentage of this is specific subgroup may disclose epilepsy-related information to teachers than that of the population (i.e., parents of children with epilepsy in general).

Still regarding Hypothesis 1, it was hoped that degree to which parents struggled with their disclosure decision might prove informative, even though all parents in this study did in fact disclose. Nonetheless, the data suggests that, overall, parent-participants equivocated very little while deciding whether or not to disclose their children's epilepsy diagnosis. Most (69% of participants) reported no difficulty with the decision to disclose. Moreover, less than one-fifth of parent-participants cited this decision as "slightly difficult," and none of them reported considering it "very difficult." This information augments the implications garnered from the fact that all participants reported disclosure, suggesting that, at least within the limited sample, parents of children with epilepsy are readily disclosing their children's diagnoses to teachers.

Hypothesis 2 was left unaddressed because the data analysis intended to speak to this hypothesis was impossible to conduct (i.e., variability in parental disclosure was a precondition for this analysis and there was no variability in parental disclosure).

In correspondence with Hypothesis 3 was the finding that parents tended to indicate more ease of disclosure when their concern for their children's safety at school was greater. However, the strength of this relationship was weak and not statistically significant. This is a new finding, as a potential link between parent-school communication regarding epilepsy and parents' worries about seizure-

related injuries has not been examined in previous research. There was not support for Hypothesis 4. In fact, parents who were more concerned about epilepsy-related academic problems indicated greater difficulty in disclosing. Although conclusions are quite limited due to the small effect and sample size in this study, these results suggest that, in this limited sample, parent-participants who were more concerned about epilepsy-related threats to their children's academics did not feel that teachers' knowledge of their children's diagnosis would lead to improvements in their educational environment. Exact parental reasoning associated with this is not clear. Potential rationales are that parents do not believe epilepsy-specific classroom interventions exist or if they do exist are more beneficial than those generic interventions teachers may devise independent of knowing that epilepsy is present.

Regarding Hypothesis 5, the relationship between parents' perceptions of risks for stigmatization and their struggles over disclose, no statistically significant association was detected. Nonetheless, as predicted, these variables were positively associated with one another ($r_s = 0.31$). Although only limited conclusions can be drawn from this finding, considering the minimal effect size, it suggests that parents' perceptions of epilepsy-related discrimination at school may prompt withholding potentially stigmatizing disclosure. Potential explanations for the connection between these two phenomena, such as parental fear of stigmatization leading them to withhold epilepsy-related information from teachers, cannot be inferred from this limited dataset. This supposition would, however, coincides with parents' reports of keeping their children's epilepsy a

secret because they fear of differential treatment from others (e.g., Baker and colleagues, 2007). Whether or not these “others” include teachers remains elusive.

In addition to results garnered from data used to examine the five main hypotheses, some descriptive statistics concerning the three parent perception variables (i.e., parental concern about safety, academic problems, and stigma related to children’s epilepsy diagnosis) are of interest. Concerning the risk of seizure-related injury to parent-participants’ children, the parents’ mean level suggests moderate to significant worry. This data suggest that safety at school is a relatively important issue for parents of children with epilepsy, a conclusion that complements findings gathered from Hoar and colleagues (2000). In that study, parents were most concerned about the risk of academic difficulties, as their mean level of concern fell at “significantly worried.” In agreement with that of Baker and colleagues (2008), these data indicate that parents are well aware of the potential presence of epilepsy-related classroom difficulties. This might be interpreted as a positive sign, indicating that important research-related information is finding its way to parents. The sources from which parents are gathering this information (e.g., pamphlets, physicians, educators, websites, research articles, etc.) remains unknown.

Lastly, this study suggests that these parents were less occupied with worries about their children being stigmatized at school (slightly less than that of the concern about seizure-related injury). This is a new finding, because no prior studies compared the extent to which parents worry about school-specific stigma, academic problems, and seizure-related injury. With a level of concern that fell

between significantly and moderately worried, however, differential treatment of children with epilepsy at school remains to be an issue for parents.

This study examined parent-teacher communication concerning students with epilepsy, as well as the link between communication and parents' concerns about three categories of risk that might affect their children at school: seizure-related injury, academic difficulties, and stigma. The rationale for such predictions originated from data that suggested educators may not attend to educationally-relevant medical information about their students with epilepsy. The hypothesis that educators may not be informed of children's epilepsy was not supported, suggesting that there may be another reason for the lack of attention given to epilepsy-related, classroom issues (e.g., side-effects of antiepileptic drugs, the possibility of in-class absence seizures). Perhaps, teachers and other school staff (e.g., school psychologists) may not be aware of such risks. Additionally, the limitation created by the choice of a dichotomous indicator of disclosure should be noted. Parents who spoke to their children's teacher about epilepsy one time were considered "disclosers" of the same sort as parents who may have kept regular communication with teachers about medical issues that could play a role in their children's classroom performance. Future studies, with larger, more representative sample sizes might ask parents about the frequency with which they speak to teachers about specific issues (e.g., anti-epileptic drugs, occurrence of seizures at home, potential for absence seizures, appearance and warning signs of oncoming seizures, typical cognitive effects, etc.).

In sum, these preliminary data suggest that parents do disclose their children's epilepsy to teachers, and they are concerned about epilepsy-related risks of injury, academic problems, and stigma affecting their children. School psychologists may take the role of ameliorating both parental concern and the actual risks for these problems by consulting with teachers regarding appropriate educational accommodations and interventions. Continued contact and information gathering with parents and, possibly, students' physicians may aid professionals in conveying the most appropriate actions to teachers. Future investigations and dissemination of information to parents and educators may improve the school-experiences of both students with epilepsy and their parents.

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APPENDIX A

EPILEPSY PARENTAL CONCERN AND DISCLOSURE SCALE

Many parents find it hard to decide whether to tell schools about their child's epilepsy. Our research team is studying that topic. We would like to find out if you have told your child's teacher about your child's epilepsy diagnosis.

Telling means you did any of the following:

- Gave them anything in writing that says your child has epilepsy
- Told them (out loud) that your child has epilepsy
- Talked about seizures, epilepsy medications, or epilepsy medical appointments

Did you tell your son's or daughter's teacher about epilepsy? Please circle your response.

Yes	No
I told my child's teacher about his/her epilepsy.	I did not tell my child's teacher about his/her epilepsy.

We are also interested in how much you struggled with whether or not to tell your child's teacher about his or her epilepsy. Please circle the statement that is most true about how easy or difficult this decision was for you to make.

My decision was very easy	My decision was slightly easy	My decision was neither easy nor difficult	My decision was slightly difficult	My decision was very difficult
1	2	3	4	5

We are also interested in how much parents are concerned about different ways that epilepsy may affect their child at school. Each of the following items

are about school-related issues that might concern parents of children with epilepsy. Please indicate how much you are worried about the following potential concerns on a scale of 1 to 5, with 5 indicating the most worried.

1. I am concerned that my child may suffer an accidental physical injury at school because of epilepsy.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

2. I am concerned that my child's epilepsy will threaten his/her academic performance.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

3. I am concerned my child will be treated differently by other children at school because of his/her epilepsy.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

4. Safety at school is a big issue for me because I worry that my child will be injured during a seizure.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

5. I am concerned that my child will have trouble with schoolwork because of his/her epilepsy.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

6. Because my child has epilepsy, I am concerned that he/she will be excluded from social activities.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

7. My child's risk of accidental injury because of his/her epilepsy at school is a big concern for me.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

8. Because my child has epilepsy, I worry that his/her grades will suffer.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

9. I worry that my child will have trouble making friends because of his or her epilepsy.

not worried about this at all	slightly worried about this	moderately worried about this	significantly worried about this	very significantly worried about this
1	2	3	4	5

Table 1. Correlations Among Parental Perceptions of Epilepsy at School Items

	Sa1	Sa2	Sa3	A1	A2	A3	St1	St2	St3
Sa1	1								
Sa2	.81	1							
Sa3	.94	.88	1						
A1	.56	.47	.60	1					
A2	.57	.53	.64	.98	1				
A3	.58	.56	.64	.96	.99	1			
St1	.43	.54	.55	.43	.63	.58	1		
St2	.54	.50	.65	.63	.80	.64	.89	1	
St3	.74	.68	.85	.57	.56	.56	.70	.74	1

Notes: Column and row headings identify items, with the letter reflecting the specific Parental Perceptions of Epilepsy at School variable. Sa = parental perception regarding the risk of seizure-related injury; A = parental perception regarding the risk of epilepsy-related academic problems; St = parental perception regarding the risk of encountering social stigmatization among classmates. Relationships are represented by Spearman's rank-order correlation coefficients.

Table 2. Medians, Means, and Standard Deviations of Parental Perception of Epilepsy at School Item Scores

Risk Type	Median	Mean	SD
Seizure-related injury	3.67	3.38	1.23
Academic problems	5.00	4.02	1.55
Stigmatization	3.34	3.24	1.40

Table 3. Medians, Means, and Standard Deviations of Parental Perception of Epilepsy at School Summed Scores

Risk Type	Median	Mean	SD
Seizure-related injury	11.00	10.13	3.70
Academic problems	15.00	12.01	4.65
Stigmatization	10.00	9.73	4.20

Table 4. Response-Frequencies Regarding Difficulty of Disclosure

Level of Difficulty Associated with Disclosure	Frequency	%
Very easy	11	68.8
Slightly easy	1	6.3
Neither easy nor difficult	1	6.3
Slightly Difficult	3	18.8
Very Difficult	0	0

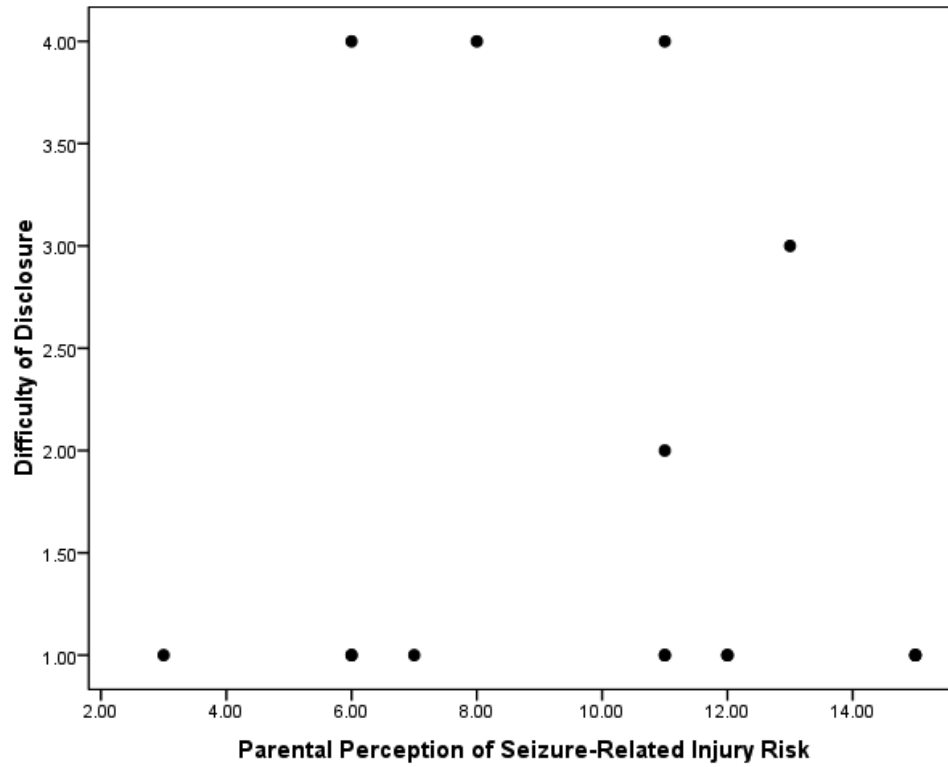


Figure 1. Scatterplot of Participants' Reported Difficulty of Disclosure and Parental Perception of Seizure-Related Injury Risk

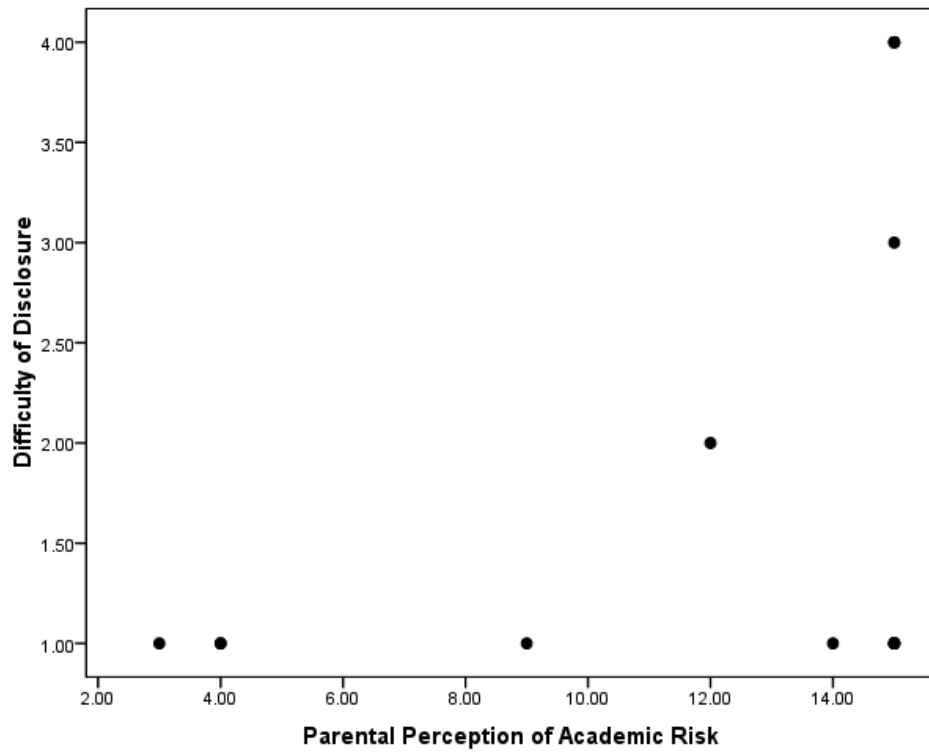


Figure 2. Scatterplot of Participants' Reported Difficulty of Disclosure and Parental Perception of Academic Risk

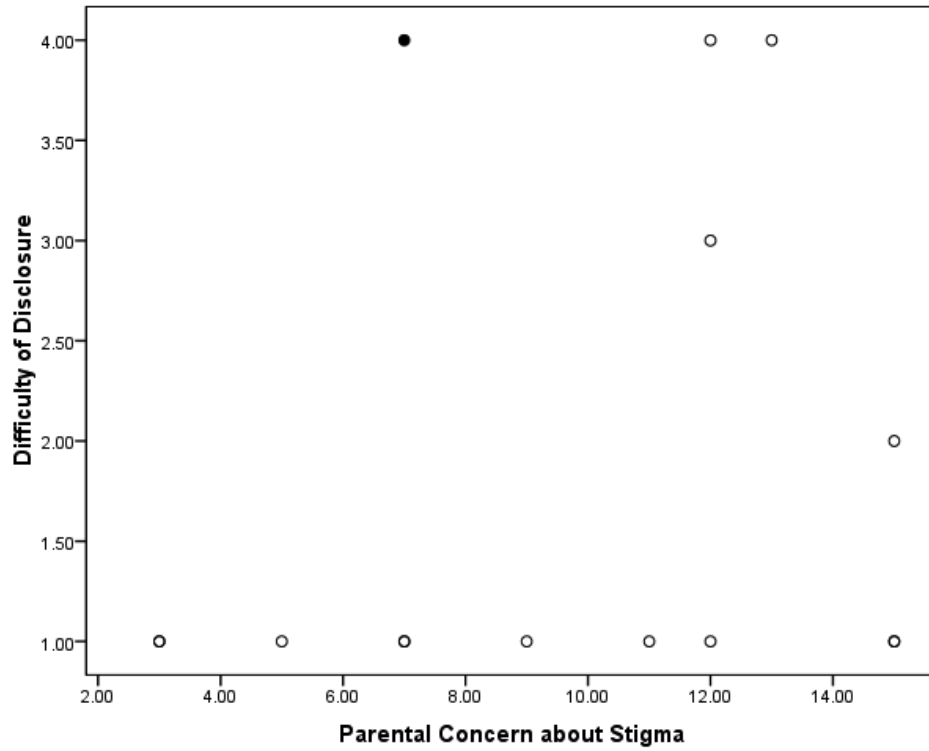


Figure 3. Scatterplot of Participants' Reported Difficulty of Disclosure and Parental Perception of Stigma Risk

