

Awareness and Access to Mental Health Care for Children and Youth with Epilepsy

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Brief description: The overall goal of this project is to improve identification and understanding of mental health problems in children and youth with epilepsy. The research on mental health problems and access to care is unfortunately limited; therefore the nature of this project is primarily qualitative, though when possible quantitative measures were utilized.

Epilepsy is a common chronic neurological disorder that is characterized by recurrent unprovoked seizures. These seizures are transient signs and/or symptoms due to abnormal, excessive or synchronous neuronal activity in the brain. The symptoms of epilepsy are complex and there are many risk factors that influence the potential to develop various forms of psychopathology (Dunn & Austin, 2004). In the United States, children and youth with epilepsy, and their families, do not access to comprehensive, culturally appropriate, community-based information and services they need to make informed choices about their health. There exist even greater barriers for children and youth with epilepsy who reside in rural or frontier areas, where there is a shortage of primary care and specialty providers.

Children and adolescents with epilepsy are at considerable risk of developing various forms of psychopathology (Buelow & McNelis, 2002; Dunn & Austin, 2004; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005; Turkey, Beavis, Thapar, & Kerr, 2008). Impairments as a result of comorbidity in these children are significantly greater than those found in children with other chronic disorders such as diabetes or asthma (Davies, Heyman, & Goodman, 2003). Barriers to obtaining mental health care have only recently been addressed, but research suggests that health care professionals should be aware of the need for adequate identification and treatment of mental health issues, particularly depression (Sample, Ferguson, Wagner, Pickelsimer, & Selassie, 2006). The importance of detection and adequate treatment of mental health problems in children and adolescence with epilepsy is highlighted by the fact that mental health issues are associated with increased health care utilization (Cramer, Blum, Fanning, & Reed, 2004; Shafer & Begley, 2000), poorer health related quality of life (Johnson, Jones, Seidenberg, & Hermann, (2004; Mikhailov, Tabulina, & Gromov, 2005), increased risk for suicidal ideation (Baker, 2006; Capaln, Siddarth, & Gurbani, 2005), and increased seizure frequency and severity (Cramer et al., 2003).

The identification of mental health disorders in youth with epilepsy poses a particular challenge and an opportunity for health care providers (Mensah, Beavis, Thapar, & Kerr, 2006). Although mental illness is a significant complication of epilepsy, there is increasing evidence that mental health problems remain unrecognized and untreated in clinical settings (Jones et al., 2005). The recognition of mental health problems in children and adolescence is largely dependent on the time and effort expended in clinical settings to assess for possible psychological comorbidity (Dunn & Austin, 2004). Health care providers may fail to consider the possibility of mood disorders or other mental health problems, which may dismissed as “normal” reaction to a chronic condition (Baker, 2006). Youth with epilepsy may express symptoms of mental illness that are unlike those

expressed by adults. For example, rather than exhibiting sadness, hopelessness, and fatigue, depressed children often engage in disruptive behavior or aggression (Kanner & Dunn, 2004). The identification of mental illness in children and adolescents with epilepsy is also complicated by the iatrogenic effects of many commonly used anti-epileptic medications (Kanner & Palac, 2000). Many antiepileptic medications, particularly, those that work with GABAergic mechanisms, have been shown to cause depressive symptoms in individuals with epilepsy (Kanner & Dunn, 2004). Moreover, antiepileptic medications that have mood stabilizing properties, such as valproic acid, can cause depressive symptoms if withdrawn too quickly (Kanner & Dunn, 2004; Plioplys, 2004).

Methods to identify youth with epilepsy at high risk of mental health problems in a clinic setting would help increase the recognition and treatment of comorbid disorders. The aims of this project were to (a) complete a review of available prevalence data to determine more precisely the extent to which mental health problems exist in children and youth with epilepsy in the United States, and (b) to determine whether youth with epilepsy are at increased risk for certain forms of psychopathology or whether the risk is ubiquitous for all types of psychiatric problems, and (c) determine the best practices for identifying psychopathology in this population.

Methods

Larger project framework

This study is being conducted as part of a larger research project under a currently funded grant, *Improving Access to Care for Children and Youth with Epilepsy Rural and Frontier Areas (2007-2010)*. The larger aims of this project are to ensure access to an integrated system of care for children and youth with epilepsy and their families in rural and frontier areas in Alaska, California, Nevada, and Wyoming. The University of Wyoming, Wyoming Institute for Disabilities (WIND) will share tools and resources and build knowledge collectively under this research collaboration. The next step on this line of research is to examine the barriers to obtaining mental health services for youth with epilepsy. A number of evaluation strategies will be used to conduct a needs assessment of mental health care issues among children and youth with epilepsy including (a) mailed and internet based surveys, (b) interviews with local state and regional mental health care agencies, and (c) focus groups with parents of children and youth with epilepsy. Questions have already been created in collaboration with the members of the state teams of this project. The findings from this study will be used to build upon ongoing research in this area. This research has the potential to improve public awareness and training of professionals working with children and youth with epilepsy to identify mental health issues.

Review

A systematic review of the literature was completed in an attempt to determine more precisely the extent to which emotional and behavioral problems exist in children and youth with epilepsy in the United States and to identify the best practices for screening for and identifying psychopathology in this population. Articles were identified using and combining the terms *epilepsy, seizure disorder, mental health, prevalence, psychiatric disorders, comorbidity, dual diagnosis, behavior problems, emotional problems, and psychopathology* through PsychINFO, PubMed, and Cochrane review databases. Studies had to include children or adolescents with epilepsy between the ages of 4-21. Articles were selected if they reported using standardized diagnostic measures, surveys, or interviews to assess for psychopathology. In addition, the reference sections of all pertinent articles were reviewed to identify articles overlooked during the electronic database search.

Results

Prevalence of Mental Health Care Issues

Overall, the results of the review suggest that between 16 to 51% of children with epilepsy experience significant emotional and behavioral problems (Davies, Heyman, & Goodman, 2003; Dunn & Autism, 2004; Hedderick & Buchhalter, 2003; Tukey, Beavis, Thapar, & Kerr, 2008). The rates of psychopathology are higher as compared with rates obtained in the general pediatric population (8%) and children with other chronic health conditions (16%). The wide variability may be due, in part, to the nature of the seizure disorder (i.e., generalized versus partial) and the methods used to diagnose psychopathology (parent report, teacher report, self-report). Reasons for this disparity deserve further empirical investigation.

The most common forms of comorbid psychopathology in children and youth with epilepsy were depression (10-51%), anxiety (15-25%), and ADHD (12-37%). Other problems reported, though with less frequency were thought problems, social problems, as well as other internalizing and externalizing behavior. There did not appear to be differences in the rates of problems between girls and boys with epilepsy. Psychopathology, particularly depression, was more pronounced in adolescents than childhood.

Identification of mental health care problems

A key component to optimizing management is early identification of psychological disorders. Evaluations are administered to identify disturbances of cognitive functioning, learning disabilities, and psychiatric disorders (Buelow & McNelis, 2002). A complete psychological evaluation is required to accurately establish a diagnosis of a mental health problem. However, thorough mental health evaluation may not be feasible within the context of primary care. Given the significant time and effort required to complete a diagnostic assessment, standardized screening tools, could play an important role in identifying children and adolescents at risk for developing mental health problems. Standardized screening instruments for assessing psychopathology in children and adolescents are widely available and include standardized clinical interviews, parent report surveys, and child self-report forms. In the next section, some of the frequently used rating scales of child emotional and behavioral systems are reviewed. The following list is not meant to be exhaustive; rather, the list is meant to highlight a few of the most commonly used measures.

Available screening and diagnostic tools

Mini-International Neuropsychiatric Interview for Children and Adolescents (Sheehan et al., 1998). The MINI Kids is an abbreviated psychiatric interview for children ages 6 to 17 years. The interview assesses for 24 DSM-IV child and adolescent psychiatric disorders as well as the risk of suicide. Administration time is approximately 15 minutes. The MINI has demonstrated good reliability and validity in multiple domains.

The Child Behavior Checklist/Teacher Report Form/Youth Self Report (CBCL/TRF/YSR; Achenbach 1991) The CBCL, TRF, and YSR are instruments used to evaluate behavioral and social problems in children ages 4 to 16 years. The CBCL, TRF, and YSR contain eight narrowband scales: anxiety/depression, withdrawal, somatic complaints, aggression, delinquent behavior, attention problems, thought problems, and social problems. The CBCL/TRF/YSR is one of the most widely used scales for clinical and research use.

The Child System Inventory (CSI; Gadow & Sprafkin, 2002) The Child System Inventory is a DSM-IV referenced rating scale that screens for affective, behavioral, and cognitive symptoms in

children aged 3-18 years. Items are rated on a 4-point scale by either parents and/or teachers. There is also a scale for children ages 12-18 to complete. Although the parent version contains 97 items and the teacher version 77 items, the authors report that the scale can be completed in 15-20 minutes. Scores from the scale provide two components: a symptom severity scale and a symptom count. The CSI has demonstrated high internal consistency and interrater reliability for both the parent and teacher versions. It has also shown high convergent validity with other measures of child psychopathology.

The Behavioral Assessment System for Children-Second Edition (BASC-2; Reynolds & Kamphaus, 2005) The Behavioral Assessment System for Children-Second Edition offers informant rating for parents, teachers, and the child. The age range of the scale is between 2-21 years. The BASC-2 assesses for a broad range of systems including anxiety, attention, depression, learning problems, and self-esteem.

The Brief Symptom Inventory (BSI; Derogatis & Melisaratos, YEAR). The BSI is a short form of the Symptom Checklist-90-Revised. The BSI by is a well-known screening tool to assess for psychological disturbance and has been found to exhibit sufficient validity and reliability in children and adolescents with epilepsy (Endermann, 2005).

Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) The Center for Epidemiological Studies Depression Scale is a 20-item measure used to assess the frequency of depressive symptoms using a 3-point scale. Internal consistency of the CES-D with adolescent samples is high, as is test-retest reliability. The most frequently used cut-off score for the CES-D is 16, which indicates moderate depression. There is evidence that the convergent validity of the CES-D in young children is low, and that the scale does not accurately distinguish between depressed children and non-depressed children.

The Connors Parent/Teacher Rating Scales (Connors et al., 1998) The Connors Parent/Teacher Rating Scales is used to identify behavior problems in children ranging in age from 3 to 17 years. Systems are rated on a 4-point Likert scale. It is available in 3 versions, including a 10-item screening version. The short version is useful when time is limited or when repeated administrations are needed.

Children's Depression Inventory (CDI; Kovacs, 1992). The CDI is a widely used self-rating scale of depressive symptomatology in children and adolescents. For each item, the child is asked to endorse one of three statements that best describes how he or she has typically felt over the past 2 weeks (e.g., "I am sad once in a while," "I am sad many times," or "I am sad all the time"). Each response is scored as either 0 (asymptomatic), 1 (somewhat symptomatic), or 2 (clinically symptomatic), contributing to an overall CDI score that can range from 0 to 54. The scale has demonstrated excellent internal consistency and acceptable test-retest reliability identified in both clinical and nonclinical samples.

Although there appear to be a number of measures available to screen for comorbid psychological in children and adolescents with epilepsy, there is little research available related to the reliability and validity in this population. Future research is needed in order to determine whether these measures can be used to accurately identify comorbid disorders in children with epilepsy.

It appears that children and adolescents with epilepsy are more likely to experience psychological difficulties than youth in the general population and children with other special health care needs. The causes of emotional and behavioral disorders remain largely unknown. A number of potential stressors specific to epilepsy may make children more vulnerable to psychological disorders. Lack of predictability of seizures and the burden of stigma associated with epilepsy are particularly prominent in promoting feelings of poor self-esteem, anxiety, and depression (Dunn & Austin, 2004). Other factors have been identified such as low socioeconomic status, cognitive impairment, and poor seizure control (Turkey et al., 2008). The presence of psychopathology is also consistently related to poorer quality of life and may further complicate seizure control (Johnson, Jones, Seidenberg, & Hermann, (2004; Mikhailov, Tabulina, & Gromov, 2005); thus prospective research is needed in order to determine more clearly the relationship between epilepsy, psychopathology, seizure control, and quality of life. Depression, ADHD, and anxiety were found to be the most prevalent form of psychopathology. The rates of these disorders in youth with epilepsy were consistently much higher as compared with rates in the general pediatric population, as well, as children and adolescents with other special health care needs.

The recognition of psychiatric disorders in children with epilepsy is largely dependent upon the time and effort physicians spend assessing for comorbid mental health problems (Dunn & Austin, 2004). Routine monitoring of psychological adjustment by physicians, nurses, and other health care providers should be a standard part of the multidisciplinary package of care for children with epilepsy (Davies et al., 2003). Although a complete psychological evaluation is required to accurately establish a diagnosis of a mental health problem, complete mental health evaluations can be time consuming and costly. Although, some argue that the long-term benefits and of regular mental health screening largely outweigh the cost associated with the test itself as well as the long-term consequences of non-treated psychopathology. Specifically, delay of diagnosis and treatment has been found to lead to more severe academic, emotional, and behavioral problems later in life (Buelow & McNelis, 2002). Physicians have the unique opportunity to assess for any dramatic change in behavioral or emotional well-being could potentially indicate the need for a more thorough mental health evaluation.

The usefulness of the available screening tools to identify children and adolescents with psychopathology appears promising. However, the validity and reliability of these measures remains less clear for this population. The sensitivity and specificity of these measures may not apply in the same manner to youth with epilepsy because of the complications inherent to the disorder itself. The information gained from broad based screening tools may be useful in guiding a clinician toward a particular problem area. In light of their heuristic value, there is a great need to examine the costs and benefits of using these screening tools in settings where youth with epilepsy are likely to receive treatment. Considering the high level of comorbidity in children and adolescent with epilepsy, there is a great need to identify screening instruments that can be routinely administered in the setting of ongoing epilepsy treatment (Endermann, 2005).

Recognition of the presence of mental health problems is only the first step. Identification must be followed by appropriate intervention. There is evidence to suggest that none of the children that had previously been identified as having a mental health problem received treatment (Davies et al., 2003; Ettinger et al., 1998). Other studies have reported similar results (Hassen-Bauer, Heyerdahl, & Eriksson, 2007). This discrepancy is disconcerting. Barriers to obtaining appropriate mental health care need to be addressed. The findings from previous research emphasize the importance of examining what physicians know about behavioral and emotional disorders in

pediatric epilepsy, their attitudes toward the need for mental health services for these children, and their knowledge of available tools to screen for these problems (Smith et al., 2007). Indeed, the results from this larger project will undoubtedly shed light on this issue. Comprehensive services are needed and should be provided to all children and adolescents with epilepsy and comorbid mental health problems. Awareness of the high rate of psychopathology in children and adolescents with epilepsy has the potential to improve many aspects of the child and families' quality of life.

Future Research

In the next few months, the Wyoming state epilepsy team, along with members of the National Epilepsy Foundation and the Regional Access to Care grant, will investigate the barriers to obtaining appropriate services by interviewing families of children with epilepsy and other seizure disorders. Rather than test a measurable hypothesis, we wanted to obtain a thorough description of the burdens specific to children/youth with epilepsy and their families living in Wyoming, with emphasis on accessibility to health and community care. The study will also target other key health care providers (i.e., primary care physicians) that serve individuals with epilepsy and their families in Wyoming to determine their perceptions of barriers that families with epilepsy face, as well as, ways to reduce those burdens. Approximately 25 families and 226 health care providers are expected to participate in the Wyoming needs assessment. The findings from this study will be used to improve access to care for children with epilepsy and their families by training primary care providers, other health care professionals, and staff of community-based agencies and programs how to identify, diagnose, and treat children/youth with epilepsy effectively.

References

- Baker, G. (2006). Depression and suicide in adolescents with epilepsy. *Neurology*, 66(6), S5-s12.
- Buelow, J.M. & McNelis, A. (2002). Should every child with epilepsy undergo a neuropsychological evaluation? *Epilepsy & Behavior*, 3, 210-213.
- Butterbaugh, G et al. (2005). Mental health symptoms in partial epilepsy. *Archives of Clinical Neuropsychology*, 20, 647-654.
- Caplan, R., Siddarth, P., Gurbani, S., Hanson, R., Sankar, R., & Shields, W. (2005). Depression and Anxiety Disorders in Pediatric Epilepsy. *Epilepsia*, 46(5), 720-730.
- Conners, C., Sitarenios, G., Parker, J. D., & Epstein, J.N. (1998). The revised *Conners Parent Rating Scale* (CPRS-R): Factor, structure, reliability, and criterion validity. *Journal of Abnormal Child Psychology*, 26, 257-268.
- Cramer, J., Blum, D., Fanning, K., & Reed, M. (2004). The impact of comorbid depression on health resource utilization in a community sample of people with epilepsy. *Epilepsy & Behavior*, 5(3), 337-342.
- Davies, S., Heyman, I., & Goodman, R. (2003). A population survey of mental health problems in children with epilepsy. *Developmental Medicine and Child Neurology*, 45, 292-295.
- Dunn, D., & Austin, J. (2004). Differential diagnosis and treatment of psychiatric disorders in children and adolescents with epilepsy. *Epilepsy & Behavior*, 5, S10-s17.
- Endermann, M. (2005). The Brief Symptom Inventory (BSI) as a screening tool for psychological disorders in patients with epilepsy and mild intellectual disabilities in residential care. *Epilepsy & Behavior*, 7, 85-94.
- Ettinger, A.B. et al. (1998). Symptoms of depression and anxiety in pediatric epilepsy patients. *Epilepsia*, 39(6), 595-599.
- Hanssen-Bauer, Heyerdahl, S., & Erikson, A. (2007). Mental health problems in children and adolescents referred to a national epilepsy center. *Epilepsy & Behavior*, 10, 255-262.
- Johnson, E., Jones, J., Seidenberg, M., & Hermann, B. (2004). The Relative Impact of Anxiety, Depression, and Clinical Seizure Features on Health-related Quality of Life in Epilepsy. *Epilepsia*, 45(5), 544-550.
- Jones et al. (2005). Screening for Major Depression in Epilepsy with Common Self-report Depression Inventories. *Epilepsia*, 46(5), 731-735.
- Kanner, A., & Dunn, D. (2004). Diagnosis and Management of Depression and Psychosis in Children and Adolescents with Epilepsy. *Journal of Child Neurology*, 19, S65-s72.
- Kanner, A., & Palac, S. (2000). Depression in epilepsy: A common but often unrecognized comorbid malady. *Epilepsy & Behavior*, 1(1), 37-51.

- Martinovic, Z., Simonovic, P., & Djokic, R. (2006). Preventing depression in adolescents with epilepsy. *Epilepsy and Behavior*, 2, 619-624.
- Mensah, S., Beavis, J., Thapar, A., & Kerr, M. (2006). The presence and clinical implications of depression in a community population of adults with epilepsy. *Epilepsy & Behavior*, 8(1), 213-219.
- Mikhailov, V., Tabulina, S., & Gromov, S. (2004). Depression as a Factor Affecting the Quality-of-Life Assessment in Patients with Epilepsy. *International Journal of Mental Health*, 33(3), 63-68.
- Plioplys, S. (2003). Depression in children and adolescents with epilepsy. *Epilepsy & Behavior*, 4, S39-s45.
- Rodenburg, R., Meijer, A.M., Dekovic, M., & Andenkamp, A.P. (2005). Family factors and psychopathology in children with epilepsy: A literature review. *Epilepsy & Behavior*, 6, 488-503.
- Sample, P.L., Ferguson, J.L., Wagner, E., Pickelsimer E. & Selassie, A.W. (2006). Experiences of persons with epilepsy and their families as they look for medical and community care: A focus group study from South Carolina. *Epilepsy & Behavior*, 9(4), 649-662.
- Shafer, P., & Begley, C. (2000). The human and economic burden of epilepsy. *Epilepsy & Behavior*, 1(2), 91-92.
- Smith, K. et al. (2007). Unmet mental health needs in pediatric epilepsy: Insights from providers. *Epilepsy & Behavior*, 11, 401-408.
- Turkey, A., Beavis, J.M., Thapar, A.K., & Kerr, M.P. (2008). Psychopathology in children and adolescents with epilepsy: An investigation of predictive variables. *Epilepsy & Behavior*, 12, 136-144.
- U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2003). *The National Survey of Children's Health, 2003*. Rockville, Maryland.
- Weisbrot, D. & Ettinger, A.B. (2001). Psychiatric aspects of pediatric epilepsy. In Ettinger, A.B., & Kanner, A.M. (eds.). *Psychiatric issues in epilepsy: A practical guide to diagnosis and treatment*. Philadelphia, PA, US: Lippincott Williams & Wilkins Publishers.