Commentary: Pediatric Epilepsy: A Good Fit for Pediatric Psychologists

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While there are an abundance of pediatric neuropsychologists working with youth with epilepsy (YWE), other subspecialty psychologists have played minimal roles in clinical and research endeavors in pediatric epilepsy. Thus, the purpose of this commentary was to describe (a) the needs of YWE due to the intermittent nature of seizures and difficulties with disease management, (b) increased risk for psychosocial comorbidities, (c) limited access to care, and (d) provide recommendations for how pediatric psychologists can become involved in the clinical care and research activities for YWE.

Introduction

While there are an abundance of pediatric neuropsychologists working with youth with epilepsy (YWE), other subspecialty psychologists have played minimal roles in clinical and research endeavors in the field of pediatric epilepsy. Our review of medical and epilepsy specific journals indeed indicates a growing literature regarding psychosocial adjustment and intervention in pediatric epilepsy; however, aside from the authors of this commentary, few of these articles are written by psychologists. Further, the flagship journal for pediatric psychology, Journal of Pediatric Psychology (JPP), published 196 empirical papers between 1998 and 2002 with 50.2% of these articles related to chronic illness (Kazak, 2002). Only eight of these papers included YWE. Of those, six papers included YWE as part of a larger cohort, leaving only two papers with significant epilepsy samples. Both of these papers were authored by health care professionals other than psychologists. Since 2002, four epilepsy empirical research articles have been published in JPP, two included solely YWE participants (Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005; Wagner, Smith, Ferguson, Horton, & Wilson, 2009), and two included YWE as part of a larger cohort.

To our knowledge only two pediatric psychology research labs in the United States (Wagner, Modi) are currently involved in psychosocial research with YWE. However, as we discuss below, the variable and intermittent nature of seizures, difficulties managing the disease, increased risk for psychosocial comorbidities, and limited access to care, combined with the scope of pediatric psychology make pediatric epilepsy an ideal area of study for pediatric psychologists.

Epilepsy and Treatments

Pediatric epilepsy, which is characterized by recurrent, spontaneous, unprovoked seizures indicating underlying cerebral dysfunction, is the most common neurological disorder of childhood. Approximately 1% of youth have pediatric epilepsy, with 60–80% having no identifiable etiology (Shinnar & Pellock, 2002). Treatments for epilepsy consist of anti-epileptic drugs (AED), vagus nerve stimulation (VNS), surgery, and diet modifications. While epilepsy treatments can improve mood and behavior, AEDs in particular, may also cause cognitive and behavioral side effects in youth (Glauser, 2004). It is important to note that...
Adherence and Self-management

Poor adherence to the treatment regimen is one component of epilepsy self-management (ESM) and has been cited as the single greatest cause of treatment failure. Non-adherence rates for AED therapy in YWE are problematic (Asato et al., 2009; Hazzard, Hutchinson, & Krawiecki, 1990; Mitchell, Scheier, & Baker, 2000), with one recent study finding rates of approximately 21% when using objective electronic monitoring data within the first month of AED therapy (Modi, Morita, & Glauser, 2008). ESM also includes adherence to lifestyle factors and coping skills, including good sleep hygiene, avoidance of seizure triggers, and stress management (Diliorio, Escoffery et al., 2009). Given the significant morbidity, mortality, and healthcare costs associated with poor adherence to ESM, it is critical to understand factors that contribute to poor adherence and develop interventions to improve adherence, and subsequently, the health and psychosocial outcomes of YWE.

Psychosocial Comorbidities

Unpredictable ongoing seizures, feelings of loss of control, and negative perceptions of epilepsy (i.e., self-efficacy for seizure management, attitudes toward epilepsy) present challenges for these youth (Austin & Caplan, 2007—see for most recent comprehensive review of psychosocial adjustment in pediatric epilepsy). In addition, several well-designed diagnostic studies have demonstrated higher rates of anxiety and affective disorders and suicidal ideation in YWE compared to healthy children (Jones et al., 2007). Similarly, meta-analyses have revealed more social problems, withdrawn behavior, inattention, and somatic complaints in YWE compared to children with other pediatric illnesses (Rodenburg, Stams, Meijer, Aldenkamp, & Dekovic, 2005). These studies demonstrate that YWE are at increased risk for psychosocial difficulties, and coping skills appear to be more critical to psychosocial adjustment than illness related variables (Austin & Caplan, 2007), suggesting the importance of evidence-based psychosocial assessment and intervention for this population.

Recent research has focused on the development of a self-report depression screening tool for use in a pediatric epilepsy clinic (Smith, Ferguson, Wagner, Hall, & Wannamaker, 2010). Wagner and colleagues (Wagner et al., 2009) found that self-report of hopelessness, attitude towards epilepsy, and self-efficacy for seizure management were related to depressive symptoms in YWE. These findings highlight the saliency of epilepsy self-management interventions that assist youth in identifying epilepsy-related aspects of functioning that they can realistically exercise control and to help them alter perceptions about situations they cannot control.

Access to Care and Intervention

Up to 70% of YWE who have comorbid psychiatric symptoms do not receive adequate mental health services (Ott et al., 2003). Brief psychological services have shown feasibility in a pediatric neurology clinical setting (Wagner & Smith, 2007); however, most epilepsy clinics do not currently have the necessary resources (e.g., funding for psychological services and/or access to pediatric psychologists). Furthermore, the development of evidence-based psychosocial interventions for YWE has been minimal (Wagner & Smith, 2006), rendering such interventions a priority recommendation by the Epilepsy Foundation and American Epilepsy Society (AES).

In a few pilot studies, cognitive–behavioral self-management interventions focused on coping skill enhancement have reduced depressive symptoms and improved quality of life and self-efficacy for seizure management (Martinovic, Simonovic, & Djokic, 2006; Snead et al., 2004; Wagner, Smith, Ferguson, van Bakergem, & Hrisko, 2010). All three studies cited recruitment barriers, including lack of funding for marketing and multiple choices for intervention group meeting times. Wagner and colleagues utilized telephone-based instead of face-to-face recruitment, perhaps limiting the personal connection with families. Further, participant time commitment for intervention groups, despite potential interest in the programs, was frequently cited as a reason for study refusal. These barriers to recruitment must be addressed, and comprehensive multi-site randomized, controlled clinical trials are necessary before the effectiveness of psychosocial interventions for YWE can be determined.

To date, little work has been done to develop interventions to specifically address non-adherence to AED therapy in children, with the exception of one trial (Dawson & Jamieson, 1971). Further, only two randomized controlled clinical trials have found improvements in medication adherence in adults with epilepsy (Brown, Sheeran, & Reuber, 2009; Peterson, McLean, & Millingen, 1984). Broader interventions focused on self-management in adults with epilepsy, including WebEase, have demonstrated improvements (Dilorio, Escoffery et al., 2009; Dilorio, Reisinger,
Call to Action and Recommendations for Pediatric Psychologists

We would like to challenge the Society of Pediatric Psychology (SPP) to consider working collaboratively with neurological health care providers on research endeavors, training future pediatric psychologists, and providing clinical services for YWE. A first step could involve a dialogue with the AES. Perhaps, SPP leadership could interface with the Professionals in Epilepsy (PEC) committee of AES. The goals of this interface would be to discuss how the scope of pediatric psychology may address the psychosocial needs of YWE in an effort to educate epilepsy health care providers about the expertise of pediatric psychologists and to facilitate collaborative projects between psychologists and epilepsy health care providers. It will also be important for pediatric psychologists to be visible at the AES annual meeting by presenting research and interfacing with epilepsy health care providers. Conversely, the epilepsy health care professionals and pediatric psychologists who have expertise in psychosocial adjustment should be encouraged to submit research proposals to SPP’s annual conference for presentation via workshops or symposia. A second step would be for those pediatric psychologists who work in settings with a significant pediatric epilepsy population to create a special interest group (SIG) in SPP. This group would consist of clinicians and researchers who (a) develop and disseminate recommendations for clinical training guidelines and assessment/intervention research and (b) suggest ways for pediatric psychologists to initiate contact and interface with pediatric epilepsy health professionals. One significant challenge is the lack of pediatric epilepsy training opportunities outside of those related to neuropsychological testing, and such training experiences should be highlighted and encouraged. This SPP group could also collaborate by using common assessment tools in pediatric epilepsy clinics to enhance consistency across research and clinical endeavors. Finally, if a pediatric epilepsy SIG was created, this group could facilitate collaborations between psychologists and health care professionals by addressing challenges to reimbursement, contacting medical colleagues at institutions where psychologists are interested in becoming involved, and recommending clinical assessment and intervention tools.

More specific recommendations for the establishment of evidenced-based assessment and intervention for psychosocial adjustment in pediatric epilepsy are offered. Efficient and standardized tools which assess epilepsy-specific developmental and self-management, take into consideration potential AED side effect-psychosocial symptom overlap, and are sensitive to the measurement of clinical change must be validated in YWE. Empirically validated tools, such as the PedsQL and Pediatric Adverse Events Scale, are currently part of standard clinical practice at Cincinnati Children’s Hospital Medical Center (Modi et al., 2009; Morita, Glauzer, Altaye, Fordyce, & Holder, 2003). Similarly, Wagner and colleagues at the Medical University of South Carolina have developed and are currently testing a self-report depression screening tool for use in pediatric epilepsy clinics (Smith et al., 2010).

Expertise in the development of assessment and intervention tools falls within the scope of pediatric psychology, and enhanced involvement by pediatric psychologists in research and clinical care of YWE would contribute to gold standard care of YWE. Multi-site randomized clinical trials should be designed to examine evidence-based psychosocial self-management assessment tools and interventions tailored to YWE and their families. A related area in which pediatric psychologists could offer expertise to YWE involves assessing readiness for epilepsy surgery with evidence-based tools.

In summary, YWE could greatly benefit from the practice of pediatric psychology; however, few pediatric psychologists are currently involved with these youth. It is our hope that based on the awareness and recommendations presented in this commentary, pediatric psychologists will consider increasing their involvement with this at-risk population.

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References

