



Behavioral health referrals in pediatric epilepsy



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ARTICLE INFO

Article history:

Received 30 July 2015

Received in revised form 28 July 2016

Accepted 14 August 2016

Available online 17 August 2016

Keywords:

Behavioral health screening

Behavioral health referrals

Pediatric epilepsy

Stigma

Depression

ABSTRACT

The purpose of this study was to examine the feasibility of a behavioral health referral protocol and barriers to behavioral health care in a pediatric epilepsy clinic. A sample of 93 youth with epilepsy ages 10–17 and caregivers completed behavioral health and seizure severity measures during a routine epilepsy clinic visit. Key findings are that 47 (50.5%) of the youth screened positive for a behavioral health referral, and 35 of these youth were referred for behavioral health services. However, only 20% made and presented for the behavioral health appointment. The most commonly cited barrier for accessing and utilizing behavioral health care was stigma related- a mental health label for the child. The significance of this study lies in the revelation that solely screening for and educating caregivers about behavioral health symptoms and providing behavioral health referral information is not an ideal model. Instead, stigma related barriers point to the necessity of continued integrated physical and behavioral health care within the pediatric epilepsy visit.

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1. Introduction

Studies have demonstrated greater medical cost and health care utilization for youth with epilepsy and emotional and/or behavioral problems (Russ et al., 2012). One Canadian population based-study indicated that individuals with epilepsy continue to have unmet behavioral (e.g., mental, psychiatric) health care needs despite this higher behavioral health resource utilization (Reid et al., 2012). In fact, estimates are that only approximately one-third of youth with epilepsy who could benefit from behavioral health services receive it. (Ott et al., 2003; Caplan et al., 2004) Youth whose health care is covered by Medicaid have particularly low access to behavioral health resources (Bateman et al., 2012; England et al., 2012). Barriers to behavioral health care in youth with epilepsy include stigma, lack of resources available, hesitancy of epilepsy health care professionals to address behavioral health, communication, and health-care coverage, among others. (England et al., 2012; Vona et al., 2009; Kanner et al., 2012a)

Youth with epilepsy are at increased risk for emotional and behavioral symptoms, and these symptoms are more strongly related to long-term health-related quality of life (HRQoL) than seizure variables. (Baca et al., 2011) More specifically, a rigorous longitudinal study of 277 youth with epilepsy revealed that having a psychiatric disorder was robustly associated with worse youth HRQoL nine years later per youth and parent report. In contrast, HRQoL was not or was only minimally associated with markers of epilepsy severity. (Baca et al., 2011) Therefore, we must prevent, manage, and treat these comorbidities. This requires improving access and utilization of behavioral health care, perhaps, initiating with the pediatric neurologist. Studies have suggested that comprehensive epilepsy care should integrate screening for behavioral health comorbidities at seizure onset and be continued throughout the course of the youth's epilepsy. (Guilfoyle et al., 2012) Recent publications have encouraged the assessment of internalizing symptoms (e.g., depression) by the epilepsy health professional during routine epilepsy visits due to the high comorbidity rates and low access to behavioral health professionals (e.g., psychologists, social workers, psychiatrists). (Kanner et al., 2012a) Consensus statements have provided recommendations for the assessment of and initiation of treatment for behavioral health disorders in individuals with epilepsy. (Kerr et al., 2011; Barry et al., 2008) More

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recent publications have indicated that epilepsy providers should assess for seizure-related or anti-epileptic drug (AED) induced depressive symptoms, promote epilepsy management, and initiate medication (SSRI) treatment and/or refer for evidence-based psychological intervention for internalizing symptoms. (Bateman et al., 2012; Kanner et al., 2012a) It appears particularly important to assess behavioral health symptoms in patients with epilepsy who report high levels of AED-related adverse effects (Kanner et al., 2012b).

As an epilepsy professional community, we are charged with integrating the screening of behavioral health symptoms into a routine pediatric epilepsy visit and improving the treatment of these symptoms by increasing access to and utilization of behavioral health care (Guilfoyle et al., 2015; Guilfoyle et al., 2013). To address these critical gaps in behavioral health care of pediatric patients with epilepsy, the aims of this study were to 1) examine a referral process in youth with epilepsy who report emotional and/or behavioral symptoms during a routine epilepsy visit, and 2) to follow-up with families regarding utilization of and barriers to behavioral health care. No hypotheses were formed given that the purpose of the study was descriptive: to examination of a process of referral and barriers to utilization of behavioral health care.

2. Material and methods

The methods of this study have been previously published (Wagner et al., 2013) and are abbreviated in the following section as they pertain only to the aspects of the study examined in the current paper.

2.1. Participants

Participants were 93 children and adolescents ages 10–17 who have been diagnosed with epilepsy for at least six months (ICD 9 codes 345.0 through 345.9, and 780.3). The International League Against Epilepsy definitions of seizures and epilepsy were used to determine eligibility (Berg et al., 2010), and code 780.3 was included per epilepsy research standards for operational definitions of epilepsy (Thurman et al., 2011). Participants also have at least low average intelligence, and were able to complete paper-pencil measures. Given the cognitive requirements for valid and reliable completion of depression self-report measures in the larger study, (Wagner et al., 2013) only participants with an intelligence quotient >85 (within 1 standard deviation above and below the mean) were eligible for study participation. Cognitive ability was confirmed based on previous neurocognitive evaluations included in the electronic medical records and health care provider consultations when necessary. Exclusion criteria included an intelligence quotient <85 and/or severe mental illness (eg, psychotic disorders) that would effect the reliability of self-reporting and were ruled out by electronic medical record review.

Caregivers were fluent in English and willing to complete paper-pencil measures and a follow-up telephone interview assessing barriers to mental health care for their youth with epilepsy.

2.2. Procedure

During a routine epilepsy visit at a Comprehensive Epilepsy Center, eligible youth and caregivers were approached, and informed consent from the caregiver and assent from the child were obtained in accordance with the established methods of the Institutional Review Board. As part of the consent process, families were informed they would receive modest compensation for their time. Caregivers and youth completed self-report measures of youth's mood, behavior, and seizure severity. All self-report measures were distributed, collected, and reviewed by nursing staff as part of

routine clinic flow. Two weeks later, a subset of 30 youth were re-administered the NDDI-E-Y for reliability estimates via telephone by a trained research assistant, who was a graduate level psychology student. Within four weeks, youth were contacted by phone for administration of a standardized interview, the depression module of the K-SADS (Kaufman et al., 1997). Results for this are not addressed in this paper. A protocol was developed for handling serious or imminent concerns regarding depressive symptom or suicidal ideation endorsement, which were documented as “serious or emergent events.” Details regarding the youth report measures and procedure for collecting behavioral health data have been previously published (Wagner et al., 2013).

If a referral to a mental health professional (e.g., psychologist, counselor, psychiatrist) was indicated by responses on the questionnaires completed during the routine epilepsy visit, nursing staff assisted in facilitating appointments with those providers. For example, if a child or caregiver's responses exceeded the cut off point for a questionnaire or if a caregiver indicated to staff that his/her child needed to see a mental health professional, a referral was facilitated. If appropriate, staff called and set up the appointment (some agencies allowed this practice; others require that the caregiver call to set up an appointment). The use of the referral protocol was streamlined by providing written information about referral sources, contact numbers, etc. and a simple outcome sheet for staff to input the date, type, and method of referral. If a caregiver indicated that his/her child was already being seen by a behavioral health professional, the following was documented: the type of professional seen, frequency of appointments, reason for referral, and diagnosis. If a referral was indicated during telephone administration of the NDDI-E-Y, the research assistant provided verbal and mailed written information about referral sources.

All participants who were referred were contacted two months later to complete a semi-structured telephone interview (see in Supplementary material) assessing access and barriers to care. If participants had not yet seen a behavioral health provider, the interviewer problem-solved with the family about how to overcome barriers. A protocol was also developed for handling serious or imminent concerns during this interview. (see Fig. 1 for procedure flow chart).

2.3. Measures

In clinic, youth completed the *Neurological Disorders Depression Inventory for Epilepsy-Youth (NDDI-E-Y)*, and a response of ‘always or often’ to seven or more items, or to the item ‘I'd be better off dead’ was used to signal need for referral (Wagner et al., 2013).

In clinic, caregiver report of youth general behavioral health functioning was assessed by the *Pediatric Symptom Checklist [PSC; (Jellinek et al., 1986)]*. The PSC has been validated in youth with epilepsy (Wagner et al., 2015a), and the more conservative suggested cut-off score of 22 was used to signal a referral, or caregiver request (Anderson et al., 1999). The PSC has been validated in youth with epilepsy. Caregivers also completed the *Seizure Social Severity Scale (SSSS)*, a 9-item measure which assesses seizure severity (Austin et al., 2006). Items cover the intrusiveness of a seizure (e.g., incontinence, loss of consciousness), disruptiveness of the seizure (e.g., bizarre movements), and effects of the seizure (e.g., injury, confusion, somnolence). A four choice response format is offered, and caregivers can rate up to three seizure types. The seizure type with the highest severity score is used for the total seizure severity score for each individual.

Caregivers completed a referral questionnaire, which was administered as a structured interview via telephone. This 15-item measure was developed for the purposes of the current study to track behavioral health referrals, access to, and utilization of behavioral health care (see Supplementary material). The format

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