



## Obstacles to mental health care in pediatric epilepsy: Insight from parents

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### ABSTRACT

This exploratory study compared the responses of 20 Caucasian and 20 Hispanic mothers of children with epilepsy about possible obstacles to mental health care (MHC) for their children before and after they read a brochure on the neurobehavioral comorbidities of epilepsy. The intervention significantly increased the mothers' knowledge of the behavior and cognitive comorbidities of pediatric epilepsy and their treatment. Baseline differences in the attitude toward MHC and the stigma of epilepsy between Hispanic and Caucasian mothers were no longer apparent after the intervention. Irrespective of ethnicity, the mothers also became significantly more aware that their children did not want to have epilepsy-related behavior and learning difficulties. Efficient use of time spent in doctors' waiting rooms to educate parents about the neurobehavioral comorbidities of epilepsy can address the lack-of-knowledge barrier to MHC. However, the study's findings suggested a need to determine if there are specific obstacles to MHC in pediatric epilepsy.

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### 1. Introduction

Currently, extensive evidence from both epidemiological and community studies reveals behavior problems and psychopathology in 20 to 60% of children with epilepsy, a rate three to six times that of the general population (see reviews in [1–3]). Furthermore, the mental health needs of these children are often undiagnosed and untreated [4–7]. The discrepancy between the mental health needs of children with epilepsy and their participation in mental health services calls into question those factors that act as obstacles to mental health care (MHC).

Factors associated with MHC access among children without epilepsy who have behavioral and emotional problems include parental lack of knowledge about mental illness [8], parental beliefs and perceptions about mental health problems [8–12], the role of the primary physician in providing mental health referrals [13–15], the stigma of mental illness [8], minority status [13,19–21], and structural variables, such as insurance coverage, timing of appointments and missing work, distance from home, and available transportation (see review in [22]).

Few studies have examined what parents know about the comorbidities of pediatric epilepsy [23]. As demonstrated in children with psychiatric disorders without epilepsy [8], parents' lack of knowledge about comorbidities and unmet mental health needs

of children with special needs [24,25] might also be a potential barrier to MHC for children with epilepsy. Previous studies have found that epilepsy-based educational interventions for groups of parents of children with epilepsy significantly increased parents' knowledge about epilepsy [26–28] and the psychosocial aspects of this illness [27].

With respect to knowledge about MHC, Owens et al. [12] demonstrated that parental perceptions about mental health problems and their treatment served as significant barriers to treatment in one-third of parents interviewed using a community-based sample of children with untreated mental health needs. However, Briggs-Gowan et al. [14] found that parents who discussed behavioral and emotional problems with their children's doctors were three times more likely to seek out MHC for their children than those who did not. Yet, only 41% of parents reported having discussed behavioral and emotional problems with their primary care physicians, even though 81% were aware that they should [15].

According to the Surgeon General, the most formidable obstacle to MHC is stigma [16]. Violence and incompetence, common stereotypes linked with mental illness [17,18], create embarrassment for those with mental health needs and discourage individuals from seeking MHC [29], including the willingness to seek counseling [30]. The role of stigma is particularly important in ethnic minorities, in whom reduced MHC is related to traditional cultural rather than biopsychosocial interpretations of the need for MHC, negative parent attitude toward MHC, and reduced provision of services [13,19–21]. In fact, the stigma of mental illness, combined with the prejudice and discrimination ethnic minorities might feel

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due to group affiliation, increases the reluctance of ethnic minorities to seek MHC [31].

Similar to the prejudices associated with mental illness, individuals with epilepsy also experience stigma associated with their condition. This stigma has been cited as a significant factor in the quality of life (see review in [32]) and mental health of children with epilepsy [33]. In a survey of children and adolescents, Austin et al. [34] found that a variety of prejudices are associated with epilepsy and that these stigmatizing beliefs are related to a lack of knowledge about epilepsy. Interestingly, children with epilepsy who have more behavior problems and poor self-esteem also perceive more epilepsy-related stigma [33]. Thus, having both epilepsy and mental health problems might increase the stigma loading for these children.

The exploratory study described in this article investigated possible barriers to MHC for children with epilepsy from the perspective of Caucasian and Hispanic parents. It also determined if providing parents with information about the comorbidities of epilepsy might reduce some of these barriers. We hypothesized that Hispanic parents would be less informed about the behavioral and cognitive comorbidities of pediatric epilepsy, more reticent to have their children undergo MHC, and more aware of the stigma of both MHC and epilepsy than Caucasian parents. In addition, we posited that, irrespective of ethnicity, the educational intervention would increase parent knowledge about the psychosocial aspects of epilepsy and improve their attitude toward MHC for their children. Given the previously described role of the physician in providing mental health referrals for children [13–15], we also explored interactions between parents and providers regarding the children's behavioral and learning comorbidities.

## 2. Methods

### 2.1. Participants

We conducted this study on 20 Hispanic and 20 Caucasian mothers of children with epilepsy irrespective of the type of epilepsy and associated neurological or cognitive problems. We recruited the mothers through English and Spanish flyers distributed in the UCLA Pediatric Neurology Clinic waiting room. Mothers interested in participating in the study informed a study team member who was in the clinic waiting room to provide parents with information about the study, screen participants for the previously described inclusionary and exclusionary criteria, obtain informed consent, and give mothers the study's questionnaires and brochure, described under Procedures. She ascertained if mothers were Hispanic based on their name and use of Spanish as a first or second language. Information was unavailable on the mothers' socioeconomic status and education, as well as on the number of mothers who were uninterested in participating in the study after reading the flyers.

### 2.2. Procedures

This study was conducted in accordance with the policies of the Human Subjects Protection Committees of the University of California, Los Angeles. Informed consent was obtained from the subjects in the clinic waiting room. After signing the consent, mothers were administered the pre-intervention questionnaire. They then read a brochure about the comorbidities of pediatric epilepsy and completed the post-intervention questionnaire.

#### 2.2.1. Questionnaire

Based on information acquired from parents, pediatric neurologist, and pediatricians in prior studies [3,23,35], the 78-item Eng-

lish and Spanish surveys included questions on parents' knowledge about behavior and learning problems in children with epilepsy and treatment of these comorbidities, and related topics on which parents felt they needed more information (Table 1), as well as parents' opinion on whether seizures, behavior, learning, or both behavior and learning had the most important impact on their children's lives and their perception of this impact from their children's perspective. We also queried mothers on their attitude toward and obstacles to MHC, using a questionnaire adapted with permission from the Child and Adolescent Services Assessment (CASA) [36] (Table 2), on their interactions with their children's primary care provider on the children's behavior and learning problems [37] (Table 3), and on possible sources of stigma for their children (i.e., parents' friends, family members, neighbors, teachers, children's peers) [33,34].

The latter questions were based on evidence of the important role of the primary care physician in facilitating mental health referrals for children with behavioral and emotional problems [13–15]. Given the importance of the stigma of epilepsy and its association with the presence of behavior problems [33,34], we also included questions on possible sources of stigma for the children.

Most of the responses were measured using a 5-point Likert scale, with higher values indicating decreased likelihood and lower values indicating greater likelihood of the item. The survey also included yes/no and open-ended questions as evident from Tables 1–3.

#### 2.2.2. Brochure

The English and Spanish versions of the brochure comprised six subsections to address parents' informational needs highlighted in prior and recent studies [8,35]: behavioral and educational problems in children with epilepsy, parents' emotional difficulties dealing with epilepsy and its comorbidities, parents' priorities for their children, epilepsy-related stigma for the child, types of professionals who can assess and treat their children's behavior and learning problems, as well as sources for additional information and resources for parent support. After reading the brochure, the mothers completed the post-intervention questionnaire. With the exception of questions related to parent and provider behavior in past visits, this survey contained the same questions as the pre-intervention questionnaire.

#### 2.2.3. Linguistic equivalency of instruments and parent reading level

A Hispanic program coordinator of the Los Angeles Chapter of the Epilepsy Foundation, an expert in mental health survey instruments (M.B.T.), and a pediatric mental health services researcher (B.Z.) concluded that the study's questionnaire and brochure had linguistic equivalency and appropriate reading level (see Acknowledgments).

### 2.3. Data analysis

The questions on the parent questionnaire were grouped into eight domains, namely parents' knowledge of epilepsy and its comorbidities, parents' knowledge of MHC, parents' perception of what aspects of epilepsy were important for them and for their children, parents' attitude toward MHC, obstacles to MHC, parents' interaction with the provider about epilepsy-related behavior and learning problems in their children, providers' behavior with parents related to the children's behavior and learning problems, and the stigma of epilepsy. We then performed a principal component analysis of the measures within each domain to obtain a reduced number of outcome measures that could be compared pre- and post-intervention across parent type.

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