



Dealing with epilepsy: Parents speak up [☆]

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ABSTRACT

In this study, focus groups were used to examine parents' attitudes toward mental health services, use of mental health and other services, as well as service-related and other challenges encountered by parents of children with epilepsy. Both quantitative and qualitative analytic approaches were used to analyze the transcripts of 36 parents grouped into six focus groups by socioeconomic status (SES) (high, low) and ethnicity (African-American, Caucasian, Hispanic). The quantitative analyses demonstrated that, irrespective of SES and ethnicity, the parents were highly aware of their children's behavioral, emotional, and cognitive difficulties and the lack of knowledge about epilepsy among medical, educational, and mental health professionals. The higher-SES parents were significantly more concerned about inadequate educational services and the need for medical services, but less concerned about mental health and medical service use than the lower-SES parents. Insufficient knowledge about epilepsy and about services, parent emotional difficulties, and use of educational services differed significantly by ethnicity. The qualitative analyses highlighted the parents' concerns regarding misconceptions about epilepsy and the stigma toward mental health care among the African-American and Hispanic parents. These findings suggest the need for accessible and better-quality mental health, educational, and medical services for children with epilepsy irrespective of SES and ethnicity. They also underscore the importance of educating parents, service providers, and the general public about epilepsy.

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1. Introduction

Despite higher rates of psychopathology [1–10] and cognitive difficulties [2,7,11–13], few children with epilepsy receive mental health services [9]. A recent review of the psychosocial impact of epilepsy concluded that both families and parents of children with epilepsy would benefit from mental health services [14].

To better understand factors involved in the unmet mental health needs of children and families with epilepsy, we used focus groups to examine parents' perceptions of the need, use, and barriers to mental health care compared with the medical and educational services they receive for their children. "A focus group is defined as a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" [15]. It narrows the gap between professionals and their clients and is "a powerful means of exposing professionals to the reality" of patients' attitudes toward them and the ser-

vices they provide [16]. Moreover, focus groups allow group members to safely express their perspectives with others who share their experiences [16].

With respect to predictors of unmet mental health needs in children with epilepsy, Ott et al. [9] found that lower parental education was associated with the absence of mental health care in children with complex partial seizures and primary generalized seizures with absence. Williams et al. [10] reported that risk factors for anxiety in children with epilepsy included being Caucasian rather than African-American. In addition to child behavior problems, low income and unsatisfactory family relationships contributed to the high rate of depression in mothers of children with epilepsy [17]. This study, therefore, explored how parents' perceptions of the mental health needs of their children with epilepsy vary by socioeconomic status (SES) (e.g., high and low) and ethnicity (e.g., Caucasian, Hispanic, African-American).

Stigma is associated with mental illness and mental health care [18,19]. Yet, minorities with mental health problems appear to experience a "double stigma." More specifically, "ethnic minority groups, who might already confront prejudice and discrimination because of their group affiliation, suffer double stigma when faced with the burdens of mental health" [20]. They therefore avoid seeking mental health services [18,20]. Supporting this notion, African-Americans

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and Hispanics are less likely to use mental health services than Caucasians [21]. In addition to minorities, disadvantaged people with less education and income are more concerned about negative family reactions to mental health services [22].

On the basis of the findings from the previously reviewed studies, the study described in this article predicted that high-SES-group parents would use more mental health, medical, and educational services, have a more positive attitude toward these services, and report fewer academic, behavioral, and emotional difficulties with their children than low-SES-group parents. We also posited that Hispanic and African-American parents would use fewer mental health, medical, and educational services, adopt a more negative attitude toward these services, and report fewer academic, behavioral, and emotional difficulties than Caucasian parents. To provide a more in-depth understanding of how parents perceive mental health and other services needed for the care of children with epilepsy, we applied both a quantitative approach and a qualitative analytical approach to analysis of focus group speech samples.

2. Methods

2.1. Participants

This study included six parent focus groups stratified by SES (high, low) and ethnicity (African-American, Caucasian, Hispanic). We determined SES using the Hollingshead 2 factor index [23] which is based on parental occupational and educational status. We recruited 36 parents of children with epilepsy irrespective of the type of epilepsy and its severity, as well as comorbid mental retardation, from the UCLA Outpatient Pediatric Neurology Clinic waiting room using UCLA institutional review board-approved flyers. We did not obtain information on illness variables and the presence/absence of comorbid developmental disabilities in the children. As parents were free to pick up and respond to flyers displayed in the clinic waiting room, data on parents who refused to participate are unavailable. Because of the lower participation rate of high-SES Hispanic parents, we conducted two low-SES Hispanic parent focus groups instead of one high-SES and one low-SES Hispanic focus group. Therefore, we did not include the Hispanic parent focus groups in the between-group SES analyses.

2.2. Procedures

Three trained members of our research team, an African-American, a Caucasian, and a Hispanic group leader, each conducted two 60-minute parent focus groups (high- and low-SES groups for African-American and Caucasian parents, two low-SES Hispanic groups). During the first 10 minutes of each focus group, the group leaders introduced themselves, set the ground rules for the discussion, and had parents introduce themselves and briefly tell the group about their children with epilepsy. They then encouraged discussion on the following topics using the predetermined questions listed in Table 1: parents' knowledge about and experience with mental health, medical, and educational services for their children with epilepsy; parents' perceptions of their children's behavioral and emotional difficulties, whether these should be dealt with through mental health services, and how medical, educational, and mental health professionals, as well as people in general, viewed both pediatric epilepsy and mental illness. Although group leaders were instructed on how much time to spend on each topic (see Table 1), the group dynamics and the group leader determined the extent of discussion and amount of time spent on each question.

A facilitator audiotaped and later transcribed the conversation that took place in each focus group. Two trained raters first divided these transcripts into blocks of text based on topic change and speech turns. Within each text block, they coded for the presence or absence of the following main themes and their subcategories (Fig. 1): use of and need for mental health services, medical services, and educational services; positive, negative, and neutral attitudes toward each of the services; behavioral, emotional, and academic difficulties in the child and emotional difficulties in the parent; possible barriers to care in terms of knowledge about epilepsy or services for these children. The two raters separately coded 15% of the transcripts, and intraclass correlations indicated an interrater reliability between 0.88 and 0.99 for each theme. Each rater then proceeded to code half the remaining text blocks for all the themes.

2.3. Quantitative and qualitative data analysis

2.3.1. Quantitative

As illustrated in Fig. 1, we coded two levels of themes: main themes and subcategories. We compared the proportion of blocks of text coded for each theme subcategory (Fig. 1) across focus groups separately by SES and ethnicity. For each focus

group, the raters coded the transcript for the presence or absence of each subcategory in every text block and summed up the number of blocks in which the theme subcategory was present. Thus, for example, for the African-American groups (Fig. 1), under the main theme of Medical Use of Services, the subcategory Use was coded in 65 blocks, the subcategory Need in 8 blocks, and Other (i.e., services not wanted, discontinued, or specified) in 31 blocks. To calculate the proportion for each subcategory, we divided the frequency of blocks coded for each subcategory by the total number of blocks coded for the main theme. So, for the preceding example, for "Use" of Medical Services, we obtained $65/(65 + 8 + 31) = 62.5\%$ for the African-American groups. We then compared the variables generated for each subcategory separately by ethnicity and SES. For all quantitative analyses, exact χ^2 tests were conducted using StatXact. Significance was set at 0.05.

2.3.2. Qualitative

We searched excerpts of the coded themes for trends and relationships between SES and ethnicity groups using EthnoNotes [24], which efficiently and reliably manages, analyzes, and interprets data generated in qualitative and integrated qualitative and quantitative methods research [24].

3. Results

3.1. Quantitative results

3.1.1. Focus group differences by SES

χ^2 analyses indicated that the high-SES parents mentioned mental health, medical, and educational service use, as well as child and parent emotional difficulties, significantly less often than low-SES parents (Table 2). They discussed the need for medical services and expressed a negative attitude toward educational services significantly more often than the low-SES parents. However, we found no significant differences by SES in the attitude toward medical and mental health services, as well as in barriers.

3.1.2. Focus group differences by ethnicity

Insufficient knowledge about epilepsy and about services, parent emotional difficulties, and use of educational services differed significantly by ethnicity. Post hoc tests of χ^2 analyses showed that the African-American parents reported insufficient knowledge about epilepsy ($\chi^2(1) = 15.50, P < 0.001$), parent emotional difficulties ($\chi^2(1) = 10.58, P = 0.001$), as well as use of medical ($\chi^2(1) = 5.645, P = 0.02$) and educational ($\chi^2(1) = 5.46, P = 0.03$) services, significantly more often than Caucasian parents (Table 2). In contrast, Caucasian parents reported inadequate knowledge about services ($\chi^2(1) = 12.07, P < 0.001$) significantly more often than African-American parents. Hispanic parents mentioned use of educational services ($\chi^2(1) = 5.67, P = 0.02$) and child academic difficulties ($\chi^2(1) = 5.71, P = .02$) significantly more often than the Caucasian parents.

Additionally, there was a trend toward significant differences by ethnicity in the use of medical services (African-American > Caucasian) and child academic difficulties (Hispanic > Caucasian). Use of mental health services, attitude toward these services, and barriers, however, did not vary significantly by ethnicity.

3.2. Qualitative results

3.2.1. Mental health services and emotional difficulties

The African-American and high-SES parents were concerned about the cost and availability of mental health care through their insurance (Table 3, quotes 1 and 2). Some African-American parents also reported feeling disturbed merely by hearing that children with epilepsy might need mental health care and avoided such services (Table 3, quotes 3 and 4). In contrast, Caucasian and Hispanic parents felt that mental health services were important and helpful for their children and for the whole family (Table 3, quotes 5–7).

Parents in all the focus groups were very aware of depression in their children (Table 3, quotes 8–10), and one African-American parent reported past suicidal ideation in his child (Table 3, quote 8). Hispanic and Caucasian parents also felt that their children's

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