

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

Table 1

Topics discussed in each focus group

| |
|--|
| <p>I. Introductory questions (5 minutes)</p> <ol style="list-style-type: none"> 1. What types of services are available for children with epilepsy? (Parents need to define services) [Probe: I didn't hear anyone mention anything about mental health... What about mental health?] 2. Who do you know that has used some of these services? 3. In what ways are these services helpful or not? <p>II. Transition questions (5 minutes)</p> <ol style="list-style-type: none"> 4. What's the best way to get help for children with epilepsy? 5. What do you think a parent of a child with epilepsy should do to get help for their child? <p>III. Key questions (30 minutes)</p> <p>A. Behavior/academic challenges</p> <ol style="list-style-type: none"> 6. What challenges do children with epilepsy have that children without epilepsy do not have? 7. Please tell me what kinds of difficulties with behavior children with epilepsy are more likely to have. 8. Does epilepsy affect how children do in school? In what ways? 9. What other challenges do you think children with epilepsy have? <p>B. Services</p> <ol style="list-style-type: none"> 10. Where should parents take their children to get help for the difficulties we discussed earlier? Who do you know that has tried to get help with these difficulties for their child with epilepsy? 11. What services worked for them? What did not? 12. How do you feel/what do you think about a child with epilepsy seeing a counselor (including a psychologist, psychiatrist, social worker, religious person, marriage and family therapist, or educational therapist)? <p>C. Culture/misconceptions and stigma</p> <ol style="list-style-type: none"> 13. How knowledgeable do you think people are about epilepsy? Are they as knowledgeable as they should be? 14. How do you think people, in general, feel about children with epilepsy? 15. How do people, in general, treat children with epilepsy? How does this compare with how people generally treat other children? <p>IV. Ending questions (10 minutes)</p> <ol style="list-style-type: none"> 16. What other issues do parents of children with epilepsy have that we haven't talked about? |
|--|

self-esteem suffered as a result of their illness (Table 3, quotes 13 and 14). Moreover, Caucasian parents reported that their children felt or feared rejection from peers and also wanted to hide their illness and avoid illness-related attention (Table 3, quotes 15 and 16).

Furthermore, parents from all the groups emphasized the interaction between their own emotions and those of their children (Table 3, quotes 17–19). They pointed out that they, the parents, often expressed frustration, depression, and worries, and that these emotions affected their children negatively. Both African-American and Hispanic parents felt guilty or blamed themselves for their children's illness and problems (Table 3, quotes 20 and 21).

3.2.2. Seizures, AEDs, and behavioral difficulties

All six focus groups reported that seizures and AEDs contributed to their children's behavior problems (Table 3, quotes 22–26). In particular, Hispanic and Caucasian parents noted changes in their children's behavior from the onset of the illness and start of AED treatment. Both the high- and low-SES groups mentioned that they had mistaken their children's seizures as behavioral disturbances prior to their children's epilepsy diagnosis. Furthermore, African-American and Hispanic parents pointed out that some paramedics and mental health service providers were ignorant about epilepsy and viewed seizures as behavioral problems (Table 3, quotes 27 and 28).

3.2.3. Medical services

High-SES parents voiced financial challenges due to inadequate insurance coverage whereas low-SES parents rarely mentioned these difficulties. On the other hand, Hispanic participants also frequently stated that they did not meet qualifications for government-provided medical services for their children (Table 3, quotes 29 and 30). In terms of parents' attitudes toward medical services, African-American parents trusted their medical service

providers and thought they were "in good hands." One African-American couple even referred to their son's doctor as "the almighty something." On the other hand, Hispanic and Caucasian parents (of both high and low SES) expressed doubt in their medical service providers and thought that "the doctors know very little" and, sometimes, "parents teach the neurologists" (Table 3, quotes 31–33).

3.2.4. Educational services and academic difficulties

In excerpts coded for negative attitude toward educational services, both high- and low-SES parents felt educators were ignorant about epilepsy and how to deal with students with this illness (Table 3, quotes 34 and 35). In addition, both high- and low-SES parents repeatedly mentioned that their children lagged behind in school as a result of cognitive difficulties (Table 3, quotes 36 and 37). High-SES parents also discussed how they needed to be assertive and "literally force the school" to provide educational services for their children (Table 3, quote 38).

3.2.5. Stigma

Qualitative analyses of the transcripts also revealed several culturally specific examples of stigma. For instance, some Hispanic parents mentioned that their family members did not understand epilepsy and felt it was punishment for sins. "You know, my mom's family, they tell me 'well what did you do wrong, you know? What sin did you do that God gave your child this?'"

As mentioned earlier (Table 3, quote 4), the African-American parents (of both high and low SES) mentioned that they were raised to seek "Aunt Sally" or "the Pastor" rather than a mental health professional for help. Moreover, several African-American parents mentioned that in their culture, seizures, referred to as *spells*, were not regarded as a medical condition. "In African-American communities and churches, they (seizures) are called spells.

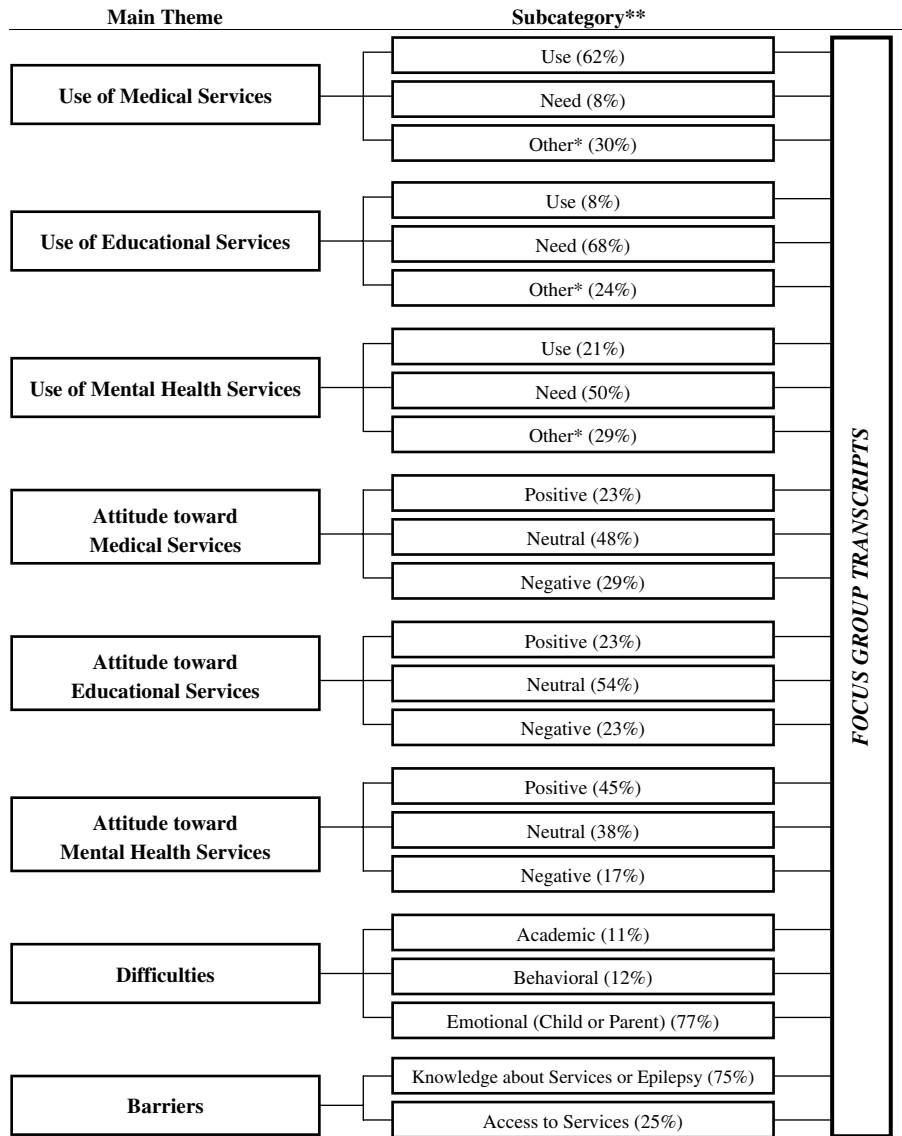


Fig. 1. Focus group themes. * Other: services discontinued, unwanted, or unspecified. ** For illustrative purposes, subcategory proportions of the African-American focus groups are included in parentheses.

Table 2
Focus group theme subcategory differences by SES and ethnicity^a

| Theme subcategory | Proportion | | | | Theme subcategory | Ethnicity | | | $\chi^2(2)$ | P value |
|---|----------------------|---------|-------------|---------|-------------------------------|-----------|--------|--------|-------------|---------|
| | Socioeconomic status | | $\chi^2(1)$ | P value | | AA | C | H | | |
| | High SES | Low SES | | | | | | | | |
| Mental Health Service Use | 12.82% | 43.48% | 7.41 | 0.01 | Epilepsy Knowledge Barrier | 58.82% | 29.63% | 38.71% | 7.85 | 0.02 |
| Medical Service Use | 40.69% | 74.73% | 26.06 | <0.001 | Service Knowledge Barrier | 15.69% | 38.27% | 25.81% | 12.06 | 0.002 |
| Educational Service Use | 48.96% | 77.27% | 9.92 | 0.002 | Parent Emotional Difficulties | 30.00% | 15.59% | 20.43% | 11.20 | 0.004 |
| Negative Attitude to Educational Services | 27.45% | 12.07% | 5.12 | 0.03 | Educational Service Use | 68.18% | 48.65% | 65.65% | 7.37 | 0.03 |
| Medical Service Need | 14.48% | 3.30% | 7.66 | 0.007 | Medical Service Use | 62.50% | 46.97% | 52.73% | 5.68 | 0.06 |
| Child Behavioral Difficulties | 9.87% | 26.83% | 17.46 | <0.001 | Child Academic Difficulties | 11.18% | 8.60% | 16.52% | 5.69 | 0.06 |
| Parent Emotional Difficulties | 17.60% | 31.71% | 9.20 | 0.003 | | | | | | |

^a This table includes only the theme subcategories that were significantly different across SES or ethnicity. AA, African-American; C, Caucasian; H, Hispanic.

As a child I had a cousin who had epilepsy. Nobody ever used the term epilepsy. That was what that was called. So we knew about it, we just didn't know the medical term for it and what we did about it was nothing. "Oh, yeah, don't worry about her Mrs. So and So, 'cause that spell will be over in just a few minutes.' She was never even medicated."

4. Discussion

4.1. Mental health service and emotional difficulties

Consistent with previous studies [1,2,4,7–10], our quantitative and qualitative analyses demonstrated that all six parent focus

Table 3
Selected quotes from focus group transcripts

| Theme | Focus Group | Quote |
|--|------------------|--|
| Mental Health Service Coverage | | |
| 1 | High SES | Once you get psychiatric disorder, and then you go see a mental health professional, anything under the umbrella of neuro-psychiatry in my insurance, I went from one hundred percent to seventy percent (insurance coverage). . . . Before my daughter came to (provider) they wanted fourteen thousand dollars prepayment upon admission. |
| 2 | African-American | Yeah, I've actually had to seek out mental health for my daughter, which has been difficult especially in an HMO system to even get that acknowledged. |
| Stigma | | |
| 3 | African-American | When you indicate mental health and when I read it, I'm going to tell you, I'm going to be honest, I was disturbed. I was like ready to walk out. To get up and leave, like this is not where I'm supposed to be. Why am I here? Why are you focusing? Why am I seeing in black-and-white "mental health?" How does this all play into what I'm getting ready to go through? Why is this spelled out "mental health?" Is it something else now that I have to think about as what we're getting ready to go through with our child? How does mental health come into epilepsy? |
| 4 | African-American | I think we as African-American aren't taught that you need other help, outside help, to go to a psychiatrist because you think maybe we're a little bit crazy. I have not found that most of the people in the community were not taught to do that. We were not raised that way. If something's wrong well talk to your Aunt Sally, or go talk to the pastor. |
| Need for Mental Health Care | | |
| 5 | Caucasian | We were interested in finding our son a therapist because all these fear issues . . . you talk about a lack of control in your life but never know when lightning will strike so we tried to find a therapist. |
| 6 | Hispanic | So there's a lot that is coming in front of him, so mental health I really need to be there for him. |
| 7 | Caucasian | Parents will go into depression. And once they're depressed they can't help their children. . . . And you know if you can't motivate the parents help their kids so the whole family needs treatment and the siblings. And you know so it's the ripple effect that the child may be the one affected but boy the whole family suffers. So I think that family mental health needs to be addressed. |
| Child Emotional Difficulties | | |
| 8 | Low SES | He was really feeling down, "something's wrong with me, am I going to make it?" That was a difficult time. |
| 9 | High SES | When she is in a depressed mood . . . and that's touchy you know. And it's almost like walking on a mine field. |
| 10 | African-American | I had to seek out mental health services for my daughter because depression was setting in and then she started talking. I know every teen goes through "I wanna die," but hers was becoming I thought more that she meant it. |
| 11 | Caucasian | Depression comes in. Frequent depression is so common in epilepsy that I think it has to be a very important component. |
| 12 | Hispanic | I can see her depressed, there's times where I can see her and she's like "what happened" she started crying. |
| 13 | Caucasian | Self-esteem is a problem too because they really see that they are about two steps behind anyone, usually because of the medication. And that's tough for kids; it's tough not to get it, not to be as quick as the other kids. So they become isolated. |
| 14 | Hispanic | My daughter's self esteem was not good anymore, it's like you can take only so much rejection. She didn't get anything . . . she just wanted a friend . . . or someone or just sit next to a table where someone would talk to you. |
| 15 | Caucasian | The thing is when the kids are older they don't identify. They're in complete denial. They live their whole life without a problem. And hers are always "I wish they were absence." They're not absence. And loses consciousness and it's obvious to everybody. |
| 16 | Caucasian | She doesn't want to be a whole seminar. She doesn't want to be probably different. Right, she doesn't want to be the center of attention because she had a seizure. So she doesn't want to feel like she's a subject of a teacher discussing her. |
| Parent Emotional Difficulties | | |
| 17 | Low SES | The kids are smart, and they pick off of everything that we feel . . . he sees or feels that you are unsure and you know you're sad about it then he pick up on. Then he'll really start to feel like something's wrong. |
| 18 | Caucasian | There's thing going on their little minds about why is mom so worried, why are they worried about money, I'm causing so many problems, everyone's stressed out. And depression you know comes in. |
| 19 | Hispanic | He knows my tone of voice when it fluctuates and I'll get mad like "why can't you just sit up? You know it'll be so much easier if you could just sit up and just not fall when you have a seizure, why?" And he looked at me and he would start to cry, "I'm sorry daddy." "I'm sorry (child's name) I was just so frustrated." |
| 20 | African-American | The onset of my child's epilepsy was from cysticercosis, which is a parasitic infection. So I have to go through the guilt because somehow I allowed this parasite to attack my child. I was obsessed with when my child hits sixteen she is going to be looking at me and saying, "why didn't you or dad do something to fix this?" Because if she is actively having seizures at 16, there is no driver's license. |
| 21 | Hispanic | It (child's behavior problems) made me feel like I didn't want to try. Guilty, they made you feel guilty. . . . They made me feel like I did something. And I just felt speechless. I felt intimidated. |
| Seizures, AEDs, and Behavioral Difficulties | | |
| 22 | Low SES | The clinginess and just the side effects or the withdrawal from the medication when she's been on something in the hospital for two or three days, which is normal . . . from what they call postictal stage and what's attributed to the drugs, what may go away when the drugs are out of her system. |
| 23 | High SES | There's a lot of behavior because we've been on the medical merry-go-round that causes social problems because of the meds. It didn't control the epilepsy, didn't control the seizures, but just made her horrible . . . irritable, hyper, up all night. |
| 24 | African-American | Epilepsy has a lot of do with behavior because we find more of his behavior a little, how can I say, I wouldn't exactly say abnormal but different. |
| 25 | Caucasian | It is involuntary our kids aren't doing it. It's the brain. So if we just let them know that, no the kids aren't being obstinate, no they don't have behavioral problems, it's probably the medication and the seizure. |
| 26 | Hispanic | He's not being a brat, or he's not just running around the classroom and not paying attention to you. There's side effects of medications you know and these are the side effects and these are the things that you can help him with. |
| 27 | African-American | The paramedics came. They just kept saying "Well, she's nonresponsive to our commands." OK, I understand that's EMT lingo. But then he kept saying, "Well, did you all discipline her? Was there a problem?" And I'm saying, "No, she has epilepsy. She had a seizure." The paramedic was like totally couldn't grasp what we were telling him and he had concluded that we must have disciplined her and that's why she was stubborn. |
| 28 | Hispanic | It was an orientation type of meeting and we walked in and they (mental health service provider) just told me that she has a behavioral problem and I said no. I said there's something and because of this I felt she needs help. And they just said no she had a behavioral problem. But they didn't even go into record or look or dig or even try. And it made me feel like "oh, I'm not going to try" you know. I go out; they told me this, imagine anywhere else I go. |
| Medical Services | | |
| 29 | High SES | As parents and trying to find services for our children . . . we don't get it covered through our insurance so my child just won't get those services. |

(continued on next page)

Table 3 (continued)

| Theme | Focus Group | Quote |
|---|------------------|---|
| 30 | Hispanic | I can't even get her to see her neurologist because she has no MediCal. She used to have MediCal, I don't know why she was taken off. |
| 31 | African-American | You're taking this doctor's advice that you know, they're the almighty something for your child at this time |
| 32 | Caucasian | I learned a painful way and quite appalled at how poorly prepared pediatricians are for kids with special needs. And I've learned also is that there are a lot of pediatricians who don't even know what seizures are. |
| 33 | Hispanic | At the beginning, you know what the doctor had to give me? A pass to the medical library. She told me I'm sorry I don't know what your daughter has, here's a pass, you're welcome to go . . . so they don't know here and the result is that we the parents teach the neurologists. |
| Educational Services and Academic Difficulties | | |
| 34 | Low SES | When you describe you know any other seizures beside a grand mal they have no clue what you're talking about. So I think the school districts again they don't know. |
| 35 | High SES | There are several different types of epilepsy and you can see it and they're all different. And when you go to the teacher and say this is the type of epilepsy, they think oh you're crazy because . . . as a whole we need to educate all the professionals that deal with our child and work as a team. |
| 36 | High SES | So she tested GATE, the high end, which was good but they couldn't understand then why her comprehension was so bad. AND what it is I think, is the memory thing. Like if you tell her a story, she may not be able to articulate it back to you in an accurate sequence or in a way that makes sense. |
| 37 | Low SES | He's failing. He's failing big time. . . . He can't focus. . . . He has like one little paragraph here you know and it will take him three hours to get this paragraph down to here. . . . Rewriting it, just because he couldn't focus. . . . We're just trying to get him to write two sentences of that, and that's still about an hour, just to write two sentences of that across there. |
| 38 | High SES | You fight with that (school aide) with the school district. You're more likely to get it (school aide) but it requires lots of letters and it requires lots. . . . You don't just get it the first time around. You gotta say no three times before somebody will listen to you. |

groups noted emotional difficulties in their children with epilepsy. The parents were also highly aware of and expressed the need to address their own emotional difficulties and the possible adverse effect on their children's emotional difficulties. Shore et al. [25] have demonstrated that the high rate of depression in parents of children with epilepsy is predicted by the children's behavior problems rather than by the severity of their epilepsy. The concurrence of higher levels of child behavior problems and parent emotional problems despite more mental health use in the low-SES parents implies a need for better-quality mental health services for low-SES parents.

We were surprised to find that the high-SES parents reported significantly less use of mental health services than the low-SES parents. This finding is likely due to the lack of insurance coverage for mental health services voiced by the high-SES parents. It stresses the importance of providing accessible mental health care to children with epilepsy and their families irrespective of SES. As suggested by the qualitative analysis, this finding might also represent the parents' lack of knowledge about the impact of epilepsy on children's behavior and emotions and the associated need for mental health services. Alternatively, the African-American and low-SES parents might have been in the earlier, more difficult stages of coping with their child's illness than the higher-SES parents. According to Austin [26], parents who adapt well to their children's seizure condition are less emotionally challenged.

Moreover, African-American parents' concerns about the stigma of mental health were consistent with the notion of a "double stigma" [20]. Facing the double stigma of mental illness and minority status, minority groups are more likely to avoid mental health services [18,20]. In fact, the African-American parents' reticence toward mental health care might have contributed to their increased reporting of emotional difficulties compared with the Caucasian parents. Furthermore, as suggested by the negative response of one of the African-American parents when mental health issues were discussed during the focus group (Table 3, quote 3), the term *triple stigma* might be more appropriate.

Although preliminary, these findings suggest that measures should be taken to educate African-American parents about the benefits of mental health services for children with epilepsy and to make these services readily available. In the absence of concerns regarding "double stigma" among the Hispanic parents, the study's findings highlight the importance of further studies of the difference in attitude toward mental health services and active seeking out of mental health care between African-American and Hispanic parents.

4.2. Medical Services

The study's medical service findings suggest an increased need for these services irrespective of SES and ethnicity. Contrary to our expectations, the high-SES parents described less use of medical services than the low-SES parents. Similar to our findings on mental health services, high-SES rather than low-SES parents were concerned about financial difficulties and inadequate insurance coverage for their children's medical care based on our qualitative analysis. It is possible that the low-SES parents in our sample might have qualified for government-funded services such as public insurance programs which help poor and low-income children gain access to medical services [27–31].

Consistent with evidence that delayed and unmet health care needs are associated with decreased trust in physicians [32], African-American parents had a more trusting relationship with their medical service providers and also used more medical services than Caucasian parents. These ethnic differences in medical service access may indicate a need for increased medical services for Caucasian parents of children with epilepsy.

4.3. Educational services

The study's findings also underscore the need for accessible educational services for both low- and high-SES children with epilepsy. Thus, although both high- and low-SES parents reported cognitive difficulties in their children, high-SES parents reported less use of educational services than low-SES parents. Moreover, high-SES parents voiced the need to assertively demand educational services for their children and were more critical of educational services than low-SES parents. The report of increased academic difficulties among the Hispanic children together with more use of educational services by their parents, most of whom were of low SES, also points to the need for better-quality educational services for these children. Supporting this finding, we previously demonstrated minority status as a predictor of cognitive and linguistic deficits in children with complex partial seizures [2].

4.4. Insufficient knowledge and misconceptions

Our findings underscore the need to provide more information about epilepsy to African-American parents of children with this illness. For African-American parents, the relationship of complete

trust in and dependence on their children's physicians suggests that in contrast to Caucasian parents, they felt they had insufficient knowledge about epilepsy and relied heavily on their physicians for this knowledge. As found in children with epilepsy and other chronic medical illnesses, acquiring knowledge of the child's medical condition, an early step in the coping process, leads to a thorough understanding of the child's condition and improves parents' ability to cope with the illness [33–36]. Information on the mean duration of epilepsy in the African-American and Caucasian children is necessary to determine if our finding reflected different phases in the coping process in these two parent groups. The Caucasian parents' reports of insufficient knowledge regarding services for their children with epilepsy implies that these parents might have been further in the coping process and had knowledge about the illness but not about related services.

In terms of misconceptions, a recent study found that U.S. Spanish-speaking adults were significantly more unfamiliar with epilepsy and had more misconceptions about the illness than non-Hispanic adults [37]. One-third of the Hispanic subjects in that study believed that people with epilepsy were dangerous, and some believed that seizures, caused by sin, could be remedied by exorcism [37]. Similarly, the African-American and Hispanic focus group parents reported misconceptions about epilepsy by family members and members of the ethnic community. Their burden was further increased given their concern that there is a lack of knowledge about epilepsy among service providers, paramedics, and teachers, as well as mental health professionals. Previous studies have reported that both teachers [38,39] and physicians [40–44] are unfamiliar with and have limited knowledge about epilepsy.

To help parents cope with stress arising from misconceptions in their communities and among service providers, it is necessary to educate African-American and Hispanic communities about epilepsy and the need for mental health services. Education about epilepsy will also better prepare front-line medical, educational and mental health service providers to provide appropriate services and support for parents of children with epilepsy.

4.5. Limitations

The study's findings represent parental perceptions and not empirical measures of service use, attitudes, and barriers. As such, they reflect the personal views of the parents participating in the focus groups. Moreover, although the group leaders tried to consistently follow the predetermined time line in Table 1, group dynamics affected the extent of discussion and time spent on each question. Variation in these two variables is an inherent problem of the quantitative statistics of focus groups.

We analyzed stigma qualitatively but not quantitatively because the low base rate with which the focus group parents made references to stigma (0 to 3 times during the entire focus group) precluded statistical analysis. The low base rate of stigma might have been a function of the fact that the group leaders introduced this topic toward the end of the focus groups so that there might have been less time to talk about stigma.

Our SES findings were limited by the absence of a high-SES Hispanic focus group and the small number of focus groups. In addition, we had no access to data on parents who decided not to participate in our study because we recruited subjects using flyers distributed by the pediatric neurologists in the UCLA Pediatric Neurology Outpatient Clinics. Furthermore, we had minimal demographic data and seizure-related information on the study participants. Thus, we do not know if parents whose children have had or currently have mental health problems, learning problems, or uncontrolled seizures were more or less motivated to participate in the study compared with other parents. Moreover, the inclusion of parents of children with intellectual disabilities in our study

could have differentially affected parents' attitudes toward and perceptions of services, as well as their knowledge about epilepsy and related challenges. However, in the absence of relevant demographic information, we were unable to investigate this question.

5. Conclusions

The quantitative and qualitative findings suggest that the parents of children with epilepsy, irrespective of ethnicity and SES, were highly aware of their children's comorbid emotional and behavioral problems and the lack of appropriate, affordable, and culturally sensitive mental health services. The findings also emphasize the concerns the parents had about the quality of the mental health, medical, and educational services their children receive. They also point to the need to educate Caucasian parents about available services, and African-American parents about epilepsy and the benefits of mental health care. The study's findings highlight the importance of providing knowledge about epilepsy to medical, educational, and mental health professionals, as well as to the African-American and Hispanic communities.

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References

- [1] Caplan R, Siddarth P, Gurbani S, Hanson R, Sankar R, Shields WD. Depression and anxiety disorders in pediatric epilepsy. *Epilepsia* 2005;46:720–30.
- [2] Caplan R, Siddarth P, Gurbani S, Ott D, Sankar R, Shields WD. Psychopathology and pediatric complex partial seizures: seizure-related, cognitive and linguistic variables. *Epilepsia* 2004;45:1273–81.
- [3] Davies S, Heyman I, Goodman R. A population survey of mental health problems in children with epilepsy. *Dev Med Child Neurol* 2003;45:292–5.
- [4] Dunn DW, Austin JK, Huster GA. Symptoms of depression in adolescents with epilepsy. *J Am Acad Child Adolesc Psychiatry* 1999;38:1132–8.
- [5] Freilinger M, Reisel B, Reiter E, Zelenko M, Hauser E, Seidl R. Behavioral and emotional problems in children with epilepsy. *J Child Neurol* 2006;21:939–45.
- [6] McCusker CG, Kennedy PJ, Anderson J, Hicks EM, Hanrahan D. Adjustment in children with intractable epilepsy: importance of seizure duration and family factors. *Dev Med Child Neurol* 2002;44:681–7.
- [7] Oostrom KJ, Teeseling HV, Smeets-Schouten A, Peters ACB, Jennekens-Schinkel A. Three to four years after diagnosis: cognition and behaviour in children with 'epilepsy only': a prospective, controlled study. *Brain* 2005;128:1546–55.
- [8] Ott D, Caplan R, Guthrie D, et al. Measures of psychopathology in children with complex partial seizures and primary generalized epilepsy with absence. *J Am Acad Child Adolesc Psychiatry* 2001;40:907–14.
- [9] Ott D, Siddarth P, Gurbani S, et al. Behavioral disorders in pediatric epilepsy: unmet psychiatric need. *Epilepsia* 2003;44:591–7.
- [10] William J, Steel C, Sharp GB, et al. Anxiety in children with epilepsy. *Epilepsy Behav* 2003;4:729–32.
- [11] Austin JK, Huberty TJ, Huster GA, Dunn DW. Academic achievement in children with epilepsy or asthma. *Dev Med Child Neurol* 1998;40:248–55.
- [12] Caplan R, Siddarth P, Bailey CE, et al. Thought disorder: a developmental disability in pediatric epilepsy. *Epilepsy Behav* 2006;8:726–35.
- [13] Mitchell WG, Chavez JM, Lee H, Guzman BL. Academic underachievement in children with epilepsy. *J Child Neurol* 1991;6:65–72.
- [14] Austin J, Caplan R. Behavioral and psychiatric comorbidities in pediatric epilepsy: toward an integrative model. *Epilepsia*, in press.
- [15] Krueger RA. *Focus groups: a practical guide for applied research*. Newbury Park, CA: Sage; 1988.
- [16] Morgan DL, Krueger RA. *When to use focus groups and why*. Newbury Park, CA: Sage; 1993.
- [17] Shore CP, Austin JK, Huster GA, Dunn DW. Identifying risk factors for maternal depression in families of adolescents with epilepsy. *J Specialists Pediatr Nurs* 2002;7:71–81.
- [18] Corrigan P. How stigma interferes with mental health care. *Am Psychol* 2004;59:614–25.
- [19] Dinos S, Stevens S, Serfaty M, Weich S, King M. Stigma: the feelings and experiences of 46 people with mental illness: qualitative study. *Br J Psychiatry* 2004;184:176–81.
- [20] Gary FA. Stigma: barrier to mental health care among ethnic minorities. *Issues Ment Health Nurs* 2005;26:979.

- [21] Narrow WE, Regier DA, Norquist G, Rae DS, Kennedy C, Arons B. Mental health service use by Americans with severe mental illness. *Soc Psychiatry Psychiatr Epidemiol* 2000;35:147–55.
- [22] Leaf PJ, Bruce ML, Tischler GL, Holzer CE. The relationship between demographic factors and attitude toward mental health services. *J Community Psychol* 1987;15:275–84.
- [23] Hollingshead A. Medical sociology: a brief review. *Milbank Mem Fund Q Health Soc* 1973;51:531–42.
- [24] Lieber E, Weisner TS, Presley M. EthnoNotes: an Internet-based fieldnote management tool. *Field Methods* 2003;15:405–25.
- [25] Shore CP, Austin JK, Dunn DW. Maternal adaptation to a child's epilepsy. *Epilepsy Behav* 2004;5:557–68.
- [26] Austin JK. A model of family adaptation to new-onset childhood epilepsy. *J Neurosci Nurs* 1996;28:82–92.
- [27] Cheng T. Children's access to four medical services: impact of welfare policies, social structural factors, and family resources. *Children Youth Serv Rev* 2006;28:595–609.
- [28] Currie J, Gruber J. Health insurance eligibility, utilization of medical care, and child health. *Q J Econ* 1996;111:431–66.
- [29] Davidoff AJ, Garrett AB, Makuc DM, Schirmer M. Medicaid-eligible children who don't enroll: health status, access to care, and implications for Medicaid enrollment. *J Health Care Org Provision Financing* 2000;37:203–18.
- [30] Eisert S, Gabow P. Effect of child health insurance plan enrollment on the utilization of health care service by children using a public safety net system. *Pediatrics* 2002;110:940–5.
- [31] Neff JM, Valentine J, Park A, Hicks-Thomas J, Christakis DA, Muldoon J. Trends in pediatric hospitalizations of children in Washington state by insurance and chronic condition status, 1991–1998. *Arch Pediatr Adolesc Med* 2002;156:703–9.
- [32] Mollborn S, Stepanikova I, Cook KS. Delayed care and unmet needs among health care system users: when does fiduciary trust in a physician matter? *Health Serv Res* 2005;40:1898–917.
- [33] Aytch LS, Hammond R, White C. Seizures in infants and young children: an exploratory study of family experiences and needs for information and support. *J Neurosci Nurs* 2001;33:278–85.
- [34] Garro A. Coping patterns in mothers/caregivers of children with chronic feeding problems. *J Pediatr Health Care* 2004;18:138–44.
- [35] Shore CP, Austin JK, Musick B, Dunn DW, McBride A, Creasy K. Psychosocial care needs of parents of children with new-onset seizures 3. *J Neurosci Nurs* 1998;30:169–75.
- [36] Taanila A, Järvelin MR, Kokkonen J. Parental guidance and counseling by doctors and nursing staff: parents' views of initial information and advice for families with disabled children. *J Clin Nurs* 1998;7:505–11.
- [37] Sirven JI, Lopez RA, Vazquez B, Van Haverbeke P. Qué es la Epilepsia? Attitudes and knowledge of epilepsy by Spanish-speaking adults in the United States. *Epilepsy Behav* 2005;7:259–65.
- [38] Bishop M, Boag EM. Teachers' knowledge about epilepsy and attitudes toward students with epilepsy: results of a national survey. *Epilepsy Behav* 2006;8:397–405.
- [39] Bishop M, Slevin B. Teachers' attitudes toward students with epilepsy: results of a survey of elementary and middle school teachers. *Epilepsy Behav* 2004;5:308–15.
- [40] Frith JK, Harris MF, Beran RG. Management and attitude of epilepsy by a group of Sydney general practitioners. *Epilepsia* 1994;35:1244–7.
- [41] Gomes MD. Doctors' perspectives and practices regarding epilepsy. *Arq Neuro Psiquiater* 2000; 58 S2:221–6. *Arq Neuro Psiquiater* 2000;58(S2): 221–6.
- [42] Marshall RM, Cupoli JM. Epilepsy and education: the pediatrician's expanding role. *Adv Pediatr* 1986;33:159–80.
- [43] Smith K, Siddarth P, Zima B, et al. Unmet mental health need in pediatric epilepsy: insights from providers. *Epilepsy Behav* 2007;11: 401–8.
- [44] Thapar AK, Scott NCH, Richens AKM. Attitudes of general practitioners to the care of people with epilepsy. *Fam Pract* 1998;15:437–42.