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How Caregivers Make Meaning of Child Mental Health Problems: Toward Understanding Caregiver Strain and Help Seeking

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Abstract

Family caregivers' conceptualizations of their child's emotional and behavioral problems (EBP) influence help-seeking for the child and caregiver strain. We analyzed 21 interviews with caregivers to explore their conceptualizations about the cause of their child's EBP, their experiences of strain, and their reported help-seeking behaviors. Caregivers had divergent conceptualizations of their child's EBP: 12 caregivers viewed the EBP as caused by a disorder and described the onset of symptoms as the central stressful event, whereas 9 caregivers described their child's problems as a response to an earlier stressor (e.g. trauma, abuse, divorce). Different patterns of caregiver strain and help-seeking were associated with caregiver conceptualization. All caregivers voiced a need for peer-to-peer support for caregivers and youth with EBP.

Family caregivers are the brokers of mental health treatment for children: caregivers find services, transport youth to and from services, and have the power to terminate services at any point (Costello, Pescosolido, Angold, & Burns, 1998; Kazdin, Holland, & Crowley, 1997; Stiffman, Pescosolido, & Cabassa, 2004). However, to seek treatment for children's emotional and behavioral problems (EBP), caregivers must first recognize symptoms and perceive those symptoms as a problem, and then they must conclude (either independently or with help from schools or law enforcement) that mental and behavioral health services should be used to address the problems (Teagle, 2002). Increasingly, caregiver conceptualization of child EBP is becoming a focus of inquiry (Angold et al., 1998; Logan & King, 2001; McKay & Bannon, 2004; Morrissey-Kane & Prinz, 1999; Teagle, 2002). The meaning that families make of a stressor has significant influence on the resources they mobilize to address its demands (e.g. help-seeking for the child and the caregiver) and the well-being of the family members (e.g. caregiver strain; McCubbin & Patterson, 1983). We analyzed interviews with caregivers of children with EPB to (a) examine caregivers' conceptualizations of their child's EPB and (b) identify patterns of help-seeking and caregiver strain related to their conceptualization. We examined caregiver's thoughts about

help-seeking for their child and the supports (informal or formal) they used to cope with their own emotional responses to the EBP.

Literature Review

Caregiver conceptualization of EBP and caregiver strain

The experience of parenting a child with EBP is presumably and demonstrably a stressful experience. Although parents acknowledge the strengths and family contributions of their children with EBP (Corman, 2009; Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998), they also report high levels of caregiving burden and strain (Angold et al., 1998; Brannan & Heflinger, 2006; Brannan, Heflinger, & Foster, 2003). However, the relationship between caregivers' conceptualization of children's EBP and their own emotional response and experience of caregiving strain remains unclear. Caregivers' conceptualizations and emotional responses fluctuate over time as they obtain a diagnosis, and accumulate more information about symptoms and prognoses (Karp, 2001; Karp & Tanarugsachock, 2000). Karp and Tanarugsachock (2001) describe four progressive stages in caregiver emotions and conceptualization, while others recognize that caregiver conceptualizations change less predictably (Logan & King, 2001; Wade, 2006) and this progression does not always lead to decreased caregiver strain or a sense of resolution (Early, Gregoire, & McDonald, 2002).

Caregiver conceptualization of EBP and help-seeking

Caregivers' recognition and understanding of their child's EBP influences the resources they mobilize (or not) to address the problem, and therefore influences help-seeking and commitment to treatment (Kazdin et al., 1997; Morrissey-Kane & Prinz, 1999; Teagle, 2002; Thompson & May, 2006). Experiences with the mental health system and other families shape whether caregivers believe the problem is caused by a chemical imbalance or other biological mechanism, a response to a stressful environment, or combinations thereof, and which resources they perceive to be most beneficial in addressing the source of the problem. Factors shaping parent's conceptualization and help-seeking behaviors include social and cultural norms (Bussing et al., 2005; Karp, 2001; Thompson & May, 2006), experiences with mental health issues (Arcia & Fernandez, 2003; Logan & King 2001), access to services, education, and severity of the child's symptoms (Angold et al., 1998; Logan & King, 2001; McKay & Bannon, 2004; Wade 2006). Some parents of ethnic/racial minority status and with less education have been shown to be less likely to perceive their children's behaviors as needing help (Bussing et al., 2005; McKay & Bannon, 2004; Thompson & May, 2006) or as a mental illness (Arcia & Fermamdez, 2003). There is no research on the effect of caregiver conceptualization of child EBP on caregiver's use of supports for her/himself. The same factors that shape help-seeking for the child likely influence caregiver's self help-seeking, along with levels of subjective caregiver strain.

To explore the role of caregiver conceptualizations of EBP further, we analyzed interviews of caregivers with children with EBP, who lived in rural areas and were enrolled in their state's Medicaid program. We examined how caregivers conceptualized their children's problems, how they reported their own stain, how they felt about help-seeking for their child, and what type of supports they activated to cope with their emotional response to their

child's problems. These issues may be particularly salient in rural areas, where mental health services are often difficult to access (Hartley, Agger, & Miller, 2002) and mental health problems may be highly stigmatized (Starr, Campbell, & Herrick, 2002).

Methods

We conducted secondary analysis of transcripts of previously conducted interviews with primary family caregivers of children with EBP. The sample was drawn from rural areas of Tennessee (TN) and Georgia (GA), and all participants' children were enrolled in Medicaid and qualified for other public services. Trained interviewers conducted a semi-structured, in-depth, face-to-face interview with the primary family caregiver in a private location of the caregiver's choosing. Interviews lasted 1–2.5 hours, and were recorded and transcribed. The initial purpose of the interviews was to understand caregivers' perceptions of available or unavailable services for children with EBP and their families in rural communities (see Murry, Heflinger, Suiter, & Brody, 2011). Respondents were reimbursed with grocery store gift certificates.

Interview questions included: Has there been a time when one of your children had EB problems? Tell me about him/her (probes: type of problems, severity, duration, impact on functioning). What do you think led to these problems? What about these problems troubles you most? What would it take her him/her to get over these problems/what would that be like? Who do you talk to about these issues? Have you talked to a medical doctor/counselor/ someone else about these problems (probes: why/why not, how was that experience for you)? What services are available in your community for these issues? What other types of services do you think would be helpful to have in your community?

Of the original 32 interviews, 21 interviews were included in this study. We excluded 11 interviews because large segments of the interviews were not recorded or the caregivers reported they were not involved in the child's life or treatment process (e.g. the child was cared for by another family member or spent several recent years in a residential treatment program). The included interviews provided a rich source for secondary analysis, as they include caregivers' descriptions of their children's symptoms, the development and history of the EBP, their help-seeking history, and their beliefs about mental health and other supportive services in their area.

Respondents

All respondents were female primary caregivers, including 16 mothers, 3 grandmothers, an aunt, and a foster mother. Of the included 21 cases, 47.6% were Caucasian, 42.9% African American, and 9.5% reported another race. Ages of the target-children with EBP ranged 4–21 years. The most common child diagnoses reported by the caregivers were attention deficit hyperactivity disorder (ADHD), depressive disorders, and conduct disorders.

Respondents were recruited for the original data collection based on three criteria: 1) they were the primary caregiver of a child who had participated in one of two longitudinal studies (see below); 2) their child was identified in the borderline or clinical range of symptomology (i.e., >63 standardized T score on internalizing or externalizing subscales) on the Child

Behavior Checklist (Achenbach, 1991); and 3) they lived in rural areas of TN or GA. TN caregivers (n=12) had been participating in a longitudinal study of Medicaid and GA caregivers (n=9) in a longitudinal study of child and family developmental processes among families who lived in poor rural counties (see Brody, Kim, Murry, & Brown, 2003). Caregivers who indicated willingness to participant in further research were recruited for these interviews.

Analysis

We used NVivo 8 to analyze interview transcripts for discussion of caregiver strain (e.g. disruption of family, demands on time, financial strain, worry, guilt, and embarrassment), formal and informal supports and help-seeking, and their explanations or conceptualizations of the cause of their children's EBP. We were particularly interested in understanding how caregivers understood their child's EBP, how they perceived their own stress, and how they sought or received support for themselves and their families. We used elements of grounded theory in analysis, including iterative coding and comparative analyses (Corbin & Strauss, 2008).

Open & axial coding—First, we used an open coding process. We separated the interviews into two sets. We read the first set to identify unexpected questions, and outline interesting categories and themes (Corbin & Strauss, 2008). Next, we conducted an axial coding process in which the initial coding scheme was expanded along properties and dimensions (Corbin & Strauss, 2008). Once this set of interviews was recoded using the axial coding scheme, the data were re-read for consistency within the codes, negative cases, and double coding. Some codes were renamed to more accurately reflect the data.

Comparative analyses—We observed divergent conceptualizations of child EBP in the data. We grouped caregivers based on their conceptualization and examined each group, focusing on within-group patterns and between-group differences. At this point, we employed constant comparison—an analytic procedure in which each incident in the data is compared with other incidents appearing to belong to the same category (Glaser & Strauss, 1967). Similarities and differences between each incident and others appearing in the same category were explored and re-categorizations were occasionally made on the basis of the comparisons.

Referential adequacy check—Findings from all interviews are presented in this paper. However, following Lincoln and Guba's (1985) recommendations for improving credibility through referential adequacy checks, half the interviews were not included in the initial analyses. Once we completed the previously described coding process with the first set of interviews, we coded the second set with the final coding scheme. Next, we categorized each of the second group of interviews based on the caregivers' conceptualization of the child's EBP (discussed further in Results). We then assessed if patterns of caregiver strain and help-seeking in the second set of interviews were consistent with those identified in the first set. All but two of the second set of interviews followed the patterns identified in the first set. The two interviews that did not reflect similar patterns deviated on only one of the two

dimensions (i.e., had unexpected patterns of help-seeking but expected patterns of strain or vice versa).

Steps to Ensure Data Accuracy—We used three methods to ensure data accuracy: peer debriefing, negative case analysis, and a referential adequacy check, discussed above (Lincoln & Guba, 1985). To improve credibility, we debriefed with two colleagues throughout data analysis—one mental health researcher and another social scientist without experience in mental health—to uncover assumptions and test conclusions. In addition, we focused on cases that did not fit expected patterns based on the literature on caregiver strain and help-seeking behaviors. Analyses were adapted to take the negative cases into consideration.

Results

The caregivers conceptualized their experiences with their child(ren)'s EBP in two different ways. Caregivers were categorized as conceptualizing the EBP as the stressful event itself, or as a response to a previous stressful event.

“EBP as Stressful Event” Conceptualization

This conceptualization is characterized by a belief that the EBP occurred unexpectedly (e.g. descriptions of the disorder happening to the child and family “out of nowhere”) and descriptions of the child’s problems being caused by the disorder. Twelve caregivers were categorized as having this conceptualization of their child’s EBP (called the “stressful event” conceptualization henceforth). Examples are shown below and in Figure 1; interviewer questions are in italics.

Tell me a little bit about the problems.

Well, [my daughter] tried to commit suicide this year...They put her in the hospital and tested her for different things. She was, when she was younger, diagnosed ADHD and anxiety disorder. And anyway, she had been falling asleep in class and missing gobs of school. And the teachers would tell me, you know, “Don’t bring her back until she gets a good night sleep.” Well, she was having good night sleeps. The problem was she was sleeping like 18 and 20 hours a day. And I kept asking them to do all these tests...you know, I think it’s probably just depression.

Tell me about his problems. How long have they been going on? What caused it?

Ever since he was five...We found out what it was called – “ADHD.”

How did you feel when they first brought the information about your child to you?

Surprised, shocked, numb. I was like “Why, why, why does he have to go through all that? What is it?” I was asking a lot of questions. And my first question was “Where did it come from? I ain’t got it. His dad never had it. So where did it come from?”

“EBP as a Response” Conceptualization

In contrast, nine caregivers described their understanding of the child’s EBP as a predictable or normative response to a previous stressful event in the family (e.g. an instance of trauma, abuse, or neglect, or a divorce or death in the family). The following quotes, in which caregivers respond to the same interview question about what led to/caused the problems, exemplify this conceptualization (called the “response” conceptualization henceforth).

What do you think led to the problems [your grandchildren] are having?

Their mother. They don’t never see their mother too much. When she comes by she don’t stay but one or two minutes to see them.

What would it take for them to be better?

Their mom to come here and be with them.

What do you think led to the problems [your children] are having?

I’m thinking it’s more [my older son’s] environment that has caused him to – Well, his father’s in prison. He has life in prison. I don’t know if that’s what he’s looking for, a father figure. I don’t know. It was more of an abusive marriage, and I’m thinking that’s why he has this hatred in him. So he don’t too much talk about it, but he’s holding in some anger...The [younger one] will cry, throw knives, come after you with a knife, I mean, that’s only because he witnessed his father come after me with knives and shooting at me and you know. So, you know, they went through a lot.

Patterns of Caregiver Strain and Help-Seeking

Once caregivers were categorized into two groups based on their conceptualization, clear patterns emerged in a) reports of or references to caregiver strain, b) caregivers’ feelings of control over help-seeking for the child, and c) type of supports sought for the caregiver (i.e., self help-seeking). Figure 2 shows the frequency counts for each construct by conceptualization group. The average number of times the construct was observed per interview is indicated at the end of each bar on the graph. As illustrated by Figure 2, every construct reported often by the stressful event group was reported infrequently by the response group, and vice versa. These patterns are best understood as overriding tendencies; for example, caregivers with a response conceptualization did not always deny that their children’s problems have strained them, but rather they more often denied experiencing strain than caregivers with a stressful event conceptualization.

As shown in Figure 2, comparative analyses revealed that caregivers with a response conceptualization were more likely to discuss a family history of abuse/neglect/trauma or other stressful family event while discussing the EBP. This supports our description of their conceptualization of the child’s EBP as a response to an earlier family stressor. They also were less likely to report feeling strained by their child’s EBP, and more likely to deny that their child’s EBP caused them personal strain. They described relatively low control over help-seeking for the child’s treatment and prognosis and were more likely to depend on informal versus formal supports for their own needs. In contrast, caregivers with a stressful

event conceptualization were likely to readily acknowledge their own strain, to describe high levels of control over help-seeking for the child's treatment and prognosis and to seek formal supports for their own needs. Neither conceptualization nor identified patterns differed consistently by race, type of mental or behavioral health problems of the target child, or state (i.e., TN and GA). However, four of the five other relative caregivers (i.e., grandparents/aunt/foster mother) were categorized as having a response conceptualization and respective patterns of strain and help-seeking. Figure 1 presents two illustrative cases for each conceptualization.

Caregiver strain—Caregivers with a stressful event conceptualization were also more likely to indicate or acknowledge experiencing high levels of strain as compared to caregivers with a response conceptualization. Their responses diverged in response to the interview question “How do these problems affect you and your family?” Caregivers with a stressful event conceptualization would usually respond to this question with a statement about their own stress, health, or financial situation. Those with a response conceptualization were more likely to focus their response on the child and/or to minimize the impact on the family or their own well-being (see Figure 1). Some caregivers with a response conceptualization directly denied that they experienced strain, for example:

His psychiatrist tried to get me to go see a psychologist, and I thought, “I got to deal with it, you know, that’s just the way it is.” And they told me, “You’re under a lot of stress from it.” I’m like, “Nah, just a little bit.” They’re like, “No, a whole lot.” I said, “No, just a little bit. We’ll be all right.” He said, “Well, how do you handle it?” I said, “Cause I have to.” You’ve got three kids, no husband. You just deal with it. You’ve just got to do it to raise your kids.

Help-seeking for child and for self—Control over the child's treatment and prognosis was expressed differentially based on conceptualizations of the child's EBP. Caregivers with a stressful event conceptualization were more likely to make statements evidencing a sense of high control. These caregivers described themselves as responsible for getting their child treatment, and exercised agency to obtain specific treatments for their child (see Figure 1). They also were more inclined to seek formal supports for their own needs, and discussed informal help-seeking much less frequently than caregivers with a response conceptualization. Formal help-seeking involves the use of medical, mental or behavioral health professionals to address problems and stressors whereas informal help-seeking includes talking to friends, family members, clergy or church members, and using prayer.

In contrast, caregivers with a response conceptualization made statements evidencing a sense of low control over their child's prognosis and treatment. These caregivers did not express the same urgency in accessing services to “fix” the symptoms; rather they made more statements indicating acceptance of the child's problems and reported more use of informal support.

Unanimous Demand for Peer-to-Peer Support

One theme did not present differently based on caregivers' conceptualization. In response to the interview question “What other types of services do you think would be helpful to have

in your community?” 15 of the 21 caregivers spontaneously indicated a need for support groups for youth and/or for caregivers. Common subthemes in requests for support groups for both youth and caregivers were 1) *meeting others like them* and 2) *replacing absent counselors in rural areas*.

We need support groups around here. I'm not talking about just for the kids. We have like, AA and...I think that's about the only one I can think of. And I'm finding out that a lot of people, not just in this county, but a lot of teenagers suffer from depression and I think that depression is a symptom of everything else that's going on with them. I think it's just one of the things that coincides with the problems. If you go to the doctor around here, the doctor will recommend going to a counselor and then [you ask]“well, can you recommend a counselor?” and they'll have like this blank stare on their face like they can't recommend one, ya know, because there's nobody here.

In addition, caregivers thought support groups for the youth would 3a) *increase social interaction and social skill building*, and support groups for caregivers would 3b) *be a forum for sharing ideas and problem solving techniques*. Caregivers felt peers could provide unique support.

I wonder if there was something like AA [Alcoholics Anonymous], that he could go every week. And maybe vent his troubles to people that...see he thinks that we're just so old that we're out of touch with everything. And it's hard for him to sit down and talk to us. And he just keeps it all bottled up and if he had somewhere with younger people that he felt comfortable with, it might be good.

Now, there needs to be a special place for people that raise grandkids. Yeah, even if they're not hyperactive [it] would be worthwhile.

Discussion

Two distinct conceptualizations of children's EBP were evident in 21 interviews with family caregivers in rural areas of TN and GA – EBP as a stressful event itself or as a response to another stressor. Our coding process and analyses developed independently of a larger study reporting similar findings (Moses, 2011). Moses (2011) examined factors related to parents' conceptualizations of their child's mental health problems and differential responses using mixed methods and a larger sample, and reported that parents' conceptualizations were either in-line with the psychiatric/medical labels (analogous to our stressful event conceptualization) or they reported alternative explanations or uncertainty about the cause of their children's problems. Parents with the other conceptualizations (i.e., alternative or uncertain) “tended to view their child's problems as reactions to life circumstances” (p.78), which was the key distinguishing feature of caregivers we categorized as having a response conceptualization. Further, Moses (2011) reported that parents' with a psychiatric conceptualization reported significantly more sadness and pessimism (i.e., indications of caregiver strain in our study) than parents with other conceptualizations, and were significantly more likely to have sought counseling for their own needs (i.e., formal help-seeking). While the labels we choose to use are different from those identified by Moses (2011), consistencies in the main findings are remarkable. Further, our findings are similar to

those of Brannan et al. (2003), who found caregiver strain was related to children's use of mental health services.

In this study, all interviewed caregivers were selected on the basis of documented high levels of EBP in the target child, indicating significant objective stressors associated with the experience of the EBP; however, these experiences appear to be less emotionally fraught for caregivers with a response conceptualization as compared to those with a stressful event conceptualization. We do not have longitudinal data on child outcomes, so we cannot assume that the children of caregivers exhibiting high control over their treatment actually had a better prognosis or fewer symptoms in the future. Our findings indicate caregivers with low control over children's treatment and prognosis reported less caregiver strain and more reliance on informal supports. One explanation for this is that some caregivers may be reluctant to report strain due to social stigmas around stress and child EBP, or because of cultural values that indicate they should not feel burdened by their children's problems. On the other hand, these caregivers might indeed feel less strained. These data do not offer any indication of levels of actual or objective strain, but, according to cognitive attribution theories, a caregiver's repeated and failed attempts to "fix" a stable behavioral or mental health problem likely lead to feelings of frustration, helplessness, and depression (Abramson, Metalsky, & Alloy, 1989). There is evidence that caregiver strain is associated with caregiver depression (Berg-Weger, Rubio, & Tebb, 2000; Brannan & Heflinger, 2001), and mediates the relationship between the severity of child mental health problems and caregiver mental health (Sales, Greeno, Shear, & Anderson 2004). If it is indeed the case that caregivers with a response conceptualization experience less strain, then their low control/low strain response may have less of a negative effect on their child's prognosis and development (Early et al., 2002). At the very least, less caregiver strain is protective for the caregiver and likely for other family members.

This is the first study, to our knowledge, to connect caregiver conceptualizations to caregivers' use of formal and informal supports (i.e., self help-seeking). Our sample described different patterns of self help-seeking based on their conceptualization of their child's EBP. This pattern is logically consistent with the patterns of caregiver strain discussed above. If a caregiver felt a high level of control in seeking formal resources for her child, and acknowledged her own strain, then she would be more likely to seek formal help for herself (stressful event conceptualization). Conversely, if a caregiver felt relatively little control over her child's prognosis, and did not recognize or experience strain, then she might be less likely to seek formal help for herself (response conceptualization). What is interesting, however, is that caregivers with a response conceptualization did not report *not* accessing supports; they just reported accessing *different* supports. Most of the research on help-seeking assumes that caregivers with high levels of objective strain, who do not seek formal help, avoid it because of stigmatization of mental health services and mental illness in their communities, leading them to deny a need for services. In this study, caregivers with a stressful event conceptualization may have viewed their informal supports as inexperienced or unsuitable for helping them cope with child EBP, whereas those who had experienced a previous family stressor (the response conceptualization) described feeling that their family, friends, and community members were capable of providing sufficient support for them as a caregiver of a child with EBP.

We were unable to explore differences in conceptualizations by type of diagnosis due to the small sample size, but Moses (2011) found no differences in parents' conceptualizations by child's diagnoses (with the exception of ADHD) or duration of the child's problems. Parents with racial/ethnic minority status and less education were less likely to have a psychiatric conceptualization (Moses, 2011). We did not find different conceptualizations by race/ethnicity in our small sample, but did find that four of five other relative caregivers had a response conceptualization.

This study has several additional limitations worth noting. First, because we used existing interview data, we were not able to ask follow-up questions for clarification. In addition, conclusive statements about the role of the caregivers' perceptions of children's EBP on the severity of caregiver strain cannot be assessed from these data, and we do not have objective measures of caregiver help-seeking for the child or for themselves. Further, while these caregivers were typical of those using publicly funded services, they may not reflect the conceptualizations of those with more resources or those more typically seen in private practice settings. Finally, the patterns discussed in these analyses were not temporally measured and causal statements cannot be made. For instance, it may be that caregivers who sought formal services perceived their child's disorder differently, and reported their own strain differently, *because* of the formal supports they used. This paper discusses formal help-seeking as the product of caregiver conceptualizations about their children's problems, but it is possible that caregivers are taught how to conceptualize their child's problems by the professionals from whom they've sought help. To this point, the stressful event conceptualization is in-line with the medical model espoused by mental health professionals.

Implications for Research & Practice

To continue to explore the importance of family conceptualization of children's mental or behavioral health problems on patterns of caregiver help-seeking and strain, we recommend the following directions for future research. Quantitative studies should explore these patterns using larger samples and valid measures of caregiver strain (e.g., Caregiver Strain Questionnaire; Brannan et al., 1997) and explore the influence of caregiver conceptualization on caregiver strain and help-seeking for both themselves and their children in conjunction with child problem severity and type of disorder. In addition, future work should assess caregiver conceptualization of children's problems upon diagnosis and over time to ascertain if conceptualizations and patterns of strain follow a developmental course or are influenced by mental health service use (Karp, 2001). Others have found that family caregivers taking care of non-biological children reported lower levels of caregiver strain on standardized measures than parent caregivers (Heflinger & Taylor-Richardson, 2004). Future research should explore other relative caregivers' conceptualizations of child EBP to ascertain if conceptualization may explain lower caregiver strain among other relative caregivers, despite other extant stressors (e.g., older age, fewer resources for more children, unexpected caregiving).

Our findings, along with those of Moses (2011), also have implication for service delivery. First, mental and behavioral health service providers should attempt to discuss the cause and meaning of child EBP with caregivers collaboratively, rather than explaining their child's

diagnosis and disorder pedagogically. A psychiatric understanding of child EBP may not be helpful for all caregivers. Second, respondents' spontaneously mentioned interest in community support groups with other families with similar experiences. Our findings suggest peer-to-peer support groups for youth and caregivers that could eventually become self-sustaining would be a valued opportunity, could use existing community organizations (e.g., churches, schools), and may be of particular salience in rural communities with scant formal resources (see Heflinger & Christens, 2006).

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EBP as Stressful Event	EBP as Response
Stressful Event Conceptualization <i>What do you think caused the problems they were having?</i> I have two boys and they were both born with attention deficit disorder...Um, I was told – my oldest son was actually tested for three days, and you know, to um, gain the diagnosis he had, and it was just part of the symptoms. It was just symptomatic of the attention deficit and it was all attributed to that. <i>Was there a specific time you first noticed these problems?</i> People would tell me this is normal behavior, but my oldest son – at 2 years-old – if I would just talk to him in a normal tone, he would kick me, hit me, bite me if it was something he didn't agree with. Then he would say "Mama, I'm sorry. I don't know why I acted like that." And I knew that was not normal. I knew there was something wrong. Acknowledged Caregiver Strain <i>How do the problems affect you and your family?</i> Stressful, very stressful. I have cried. I sit and cry sometimes and I pray a lot that they will be okay...I actually had an emotional breakdown several years back. I didn't realize I was so emotionally distraught over it. Help-seeking for Child: High Control When my children were first diagnosed with [ADHD], my oldest son was the first child at our elementary school that had it. And none of the teachers were informed on it and none of them wanted to realize it...and I had to fight at every corner, but they put him in the front of the classroom, they modified all his work, he met with the school counselor once a month. ... I would find books – from any doctors' offices, our counselor's office – and I would even take those books and leave them at the school so the teachers could be more aware of what was going on. I would go to the library, I would check out tapes or anything. Um, the 800 numbers, I would call those and ask them to send me resources...Because I believe that I am responsible and my husband is responsible. We brought those children in to the world and we are responsible for seeing to it, with everything within our power, that they become productive citizens. Help-Seeking for Caregiver: Formal Support <i>Who do you talk to about these issues?</i> I go to a counselor myself. I use the same counselor that my boys use. In fact for the last 12 years my husband and I, and the family as a whole, we've all had therapy and been counseled on how to deal with all this.	Response Conceptualization <i>Do you know what caused [your son's ADHD] problems?</i> Some of it was puberty. And then some of it was on my behalf, too...With my daughter's [depression], too. I think, truly, that the way she reacts to stuff is from what she's seen [their dad] and I react. I think they've learned from what they've seen parents – throwing things and stuff like that. I drank a lot too. I was a heavy beer drinker...So I guess a lot of [their problems] came from my behavior as well. <i>How long as [your daughter's depression] been going on?</i> Since her dad and me separated...we went from a middle class, upper-middle class standard of living, down to my income having to be the one to support the family. Now I can't give them what he would give them, so that had a lot to do with it. Denied Caregiver Strain <i>How do these problems affect you and your family?</i> I'm used to it. You know, it aggravates me, but we're used to it. Well, they get in fights, him going into their stuff, but then they go into his stuff too. So, I think it's normal the way they carry on with each other. Help-Seeking for Child: Low Control <i>What made you go and see a counselor [for your son]?</i> Because the teachers kept having problems with him. You know, getting up out of his desk and stuff. They'd send him to the bathroom, and he's over on the other side of the building talking ...Because I had figured, at first, I thought maybe it's too much work they're putting on him. Then when I put him in that EBP class, the counselors would talk to him and I had asked them, you know, I don't know what to do with him. So one of them asked me had he ever sought professional help, and I said no. That's when I started, you know, taking him to counselors. <i>How did you decide to go see a therapist with [your daughter]?</i> This happened through child services. They recommended it because of her temperament...You just don't know because, see I'm assuming that things are all right, because I haven't ever had a sickness or any problems like that. You know what I'm saying? Help-Seeking for Caregiver: Informal Support <i>Who do you talk to about these issues with your son?</i> My mom, I talked with her. She felt that he'll grow out of it. You just got to keep an eye on it and stuff.

Figure 1.

Typical cases selected to illustrate caregiver conceptualizations of child EBP and patterns of caregiver strain and help-seeking in the sample. Both cases are mothers of two children with EBP, with at least one diagnosis of ADHD, with father involvement in caregiving. Interviewer questions in italics.

Figure 2.

Frequency counts of coded references for each theme, stratified by conceptualization categorization. Avg. = Average number of times a respondent in the conceptualization category referenced the code; EBP = Emotional and behavioral problems.