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Parent-reported stigma and child anxiety: A mixed methods research study

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Abstract

Background—Stigma has been frequently cited as a barrier to service use for various mental health problems. Studies suggest that stigma may be greater for childhood mental health problems that are perceived as more atypical.

Aims—This study utilized a mixed methods research design (qual + QUAN) to examine parental endorsement of stigma and its impact on service utilization among children with significant anxiety—a common childhood problem frequently perceived as normative.

Methods—Semi-structured qualitative interviews were conducted with 29 parents of anxious children. Qualitative data were coded using a grounded theory approach, and stigma-related responses were examined for emergent themes. Quantitative data was analyzed with frequency counts and chi-square analysis.

Results—Stigma related to children's anxiety symptoms and seeking mental health services was reported by 41.3% ($n = 12$) of parents. Emergent themes included: 1) Parental Concern for Negative Consequences, 2) Parent Internalized Stigma, and 3) Negative Associations with Mental Health Treatment. Latino parents discussed stigma more frequently than non-Latino White parents (70% vs. 17.6%, respectively, $\chi^2(1, N = 27) = 5.33, p < 0.05$).

Conclusions—Although anxiety is a common childhood problem, stigma is still frequently reported by parents and may be an important barrier to mental health service use, especially among Latino youth.

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None for any author.

Keywords

Stigma; Child anxiety; Service utilization; Ethnic minority youth; Mixed methods research

1. Introduction

Stigma has historically been defined as an attribute that is deeply discrediting and makes an individual different and less desirable (Goffmann, 1980). More recent conceptualizations include the role of stigma in labeling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001). The negative influence of stigma is well established in the adult mental health literature (Alonso, Bruffaerts, Posada-Villa, et al., 2008; Henderson, Evans-Lacko, & Thornicroft, 2013; Parcesepe & Cabassa, 2013) however less attention has been directed toward the impact of mental health stigma among children, particularly youth with anxiety disorders. This is concerning given that anxiety disorders are the most prevalent disorder of childhood and associated with significant short and long term impairment (Costello, Egger & Angold, 2005; Hale, Raaijmakers, Muris, Hoof & Meeus, 2008; Merikangas, 2005; Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015). Further, despite the remarkable presence of anxiety disorders, findings suggest that children with anxiety disorders are undertreated, particularly in comparison to children with ADHD or major depression (Chavira, Stein, Bailey & Stein, 2004; Merikangas et al., 2011). While reasons for underutilization are multiple and complex, stigma may be an important factor to consider among anxious youth, yet few studies exist in this regard.

Existing findings on child mental health stigma suggest that youth with mental health problems experience shame and secrecy about having a mental illness and using psychiatric medications (Kranke, Floersch, Townsend, & Munson, 2010). Further, mental health stigma may raise concerns about being different from peers (Chandra & Minkovitz, 2007). Studies have also examined adults' perceptions of children with mental health problems. The National Stigma Study-Children (NSS-C; Pescosolido, Perry, Martin, McLeod, & Jensen 2007), used a vignette methodology to assess adult perceptions of stigma ($n = 1393$) for children with attention deficit/hyperactivity disorder (ADHD), depression, a physical disorder, and normal "daily troubles." In this study, 45% of the participants believed that receiving mental health treatment would make a child an outsider at school, 45% believed that the child would suffer as an adult if others were to discover he/she received mental health treatment as a child, and 36% of the participants reported that getting mental health treatment for a child would make a parent feel like a failure. In addition, findings suggested that adults prefer social distance from children labeled as "mentally ill" and are more reluctant to have their own children interact with a child who has a mental illness, such as ADHD or depression (Martin, Pescosolido, Olafsdottir, & Mcleod, 2007). Moreover, stigmatization was found to increase when a child's presenting symptoms were perceived as more severe or outside the realm of "normative" child behavior (Martin et al., 2007).

Parents' perceptions of mental health disorders and mental health service use may play a uniquely essential role in a child's emotional well-being. Children often rely on their parents or caregivers to identify the presence of mental health symptoms and subsequently take

action in the help-seeking process (Puustinen, Lyyra, Metsäpelto, & Pulkkinen, 2008; Sayal, 2006; Shanley, Reid, & Evans, 2008). That is, parents and caretakers act as “gateway providers” to mental health service utilization, given that they often initiate or direct the path of treatment for their child (Stiffman, Pescosolido, & Cabassa, 2004). Therefore, pathways to treatment in the mental health service system are often shaped by parents' attitudes and understanding of mental health disorders and services (McKay & Bannon, 2004; Stiffman et al., 2004). Previous studies have found that stigma-related beliefs among parents discourage help-seeking behaviors and lessen the likelihood of appropriate mental health service use (dosReis, Barksdale, Sherman, Maloney, & Charach, 2010; Hinshaw, 2005; Mukolo, Heflinger, & Wallston, 2010; Pescosolido, Martin, Lang, & Olafsdottir, 2008). It is likely that parents' stigmatizing beliefs about mental health services impact their role as gateway providers. Yet, few studies have focused on the influence of parental stigmatizing beliefs about their child's anxiety disorders and service utilization.

Findings also suggest that a parent's ethnicity differentially impacts stigma associated with mental health treatment in children. For example, in a study of 238 caregivers, stigma was associated with a lower parent-reported likelihood of help-seeking for Hispanic Americans, but not for European Americans or African Americans (Turner, Jensen-Doss, & Heffer, 2015). In another quantitative study, caregivers ($n = 275$) reported more socioeconomic and stigma-related barriers to obtaining mental health services than medical services, and Hispanic parents reported these barriers as more inhibiting than did African-American parents (Young & Rabiner, 2015).

The current study adds to the existing stigma literature by using a data-transformation variant of the convergent parallel mixed methods research (qual + QUAN) approach to examine the presence of stigma among parents of anxious children, as well as its potential impact on service utilization (Creswell & Plano Clark, 2011) in a sample of diverse youth. No studies to our knowledge have examined the construct of mental health stigma utilizing a mixed methods research design in a sample of parents of anxious youth. Utilizing a convergent mixed methods research (MMR) approach of this nature is important for gaining greater clarity on stigma, as the qualitative approach relies on the terminology and conceptualization from parents' point of view and to develop a complete understanding of parental perceptions of stigma related to their child's anxiety disorder and mental health service utilization. In the presence of ethnic differences in stigma, the current study also attempts to understand the role of race/ethnicity on stigma endorsement in this sample.

2. Method

2.1. Participants

Parents of approximately 300 children in two pediatric primary care clinics were sent a mailing by their pediatrician that included the Screen for Anxiety and Related Disorders (Birmaher et al., 1999; Birmaher et al., 1997), which is a brief parent-reported anxiety measure, a questionnaire about service utilization, and a consent-to-contact form (see Quantitative Measures for more details, below). All families with a child in the targeted age were sent the initial screening packet by the primary care clinic. One hundred and twenty five parents (42%) returned the questionnaires to the research team and 47 children scored

above the cutoff on the anxiety screening questionnaire. The research team contacted the 47 eligible families, and 29 agreed to participate (62%). Informed consent was attained from the parent before any subsequent study procedures were initiated. All study procedures were approved by the IRB for all participating institutions. All materials were available in English and Spanish so as to maximize recruitment of Latino participants. Parents who completed the screening questionnaires were provided a \$5 honorarium each for their time and effort. Parents received a \$20 honorarium for participation in the qualitative interviews.

2.2. Quantitative measures

2.2.1. Screen for Anxiety and Related Disorders (SCARED)—The SCARED-5 item version was used as a screening questionnaire (Birmaher et al., 1997; Birmaher et al., 1999). The measure consists of 5 items that loaded highest on each of the factors in a discriminant function analysis of the longer version (Birmaher et al., 1999). The SCARED-5 item has a classification rate of 78% when discriminating “anxiety” from “no anxiety” (Birmaher et al., 1999).

2.2.2. Service utilization—The Service Utilization questionnaire was used as an outcome measure. Basic service utilization items were included in order to identify families with met and unmet treatment needs. Parents were provided a set of instructions to help define “anxiety” as well as “mental health services”, and then asked about the utilization of services. Example of these items included: “Have you ever received a referral for your child for any treatment or help for emotional or behavioral problems?”; “Has your child ever received counseling/therapy for emotional or behavioral problems?”; and “Has your child ever received medication for emotional or behavioral problems?” If the parent responded “Yes” to the initial prompts, he/she was asked to select if the referral/service for their child was for problems with feeling nervous, fearful, stressed or anxious.

2.3. Qualitative interview

2.3.1. Interview guide development—The purpose of the qualitative interview was to gather a richer understanding of parent's conceptualizations of anxiety and to assess factors that facilitate and/or inhibit receiving mental health services for children who have anxiety symptoms. Topics included parental conceptualizations of anxiety, beliefs about causes, perceptions of treatment, and perceived barriers to service utilization. In order to generate new insights and potential thematic areas, general questions were asked, such as: 1) “What concerns you most about your child?”; 2) “Why do you think your child has anxiety?”; 3) “What do you think about treatments for your child's anxiety?”; and 4) “What, if anything, has made it difficult for you to get services for your child's anxiety symptoms?” Within each topic area, open-ended questions typically were asked before closed-ended questions so as not to bias a respondent's answers. The initial open-ended format allowed researchers and respondents the opportunity to explore new leads and related topics. This focus of the qualitative interview was on barriers to service use broadly, and consequently not all parents were directly asked about stigma. Leaders in the field of child anxiety and health services research reviewed the interview guide to ensure appropriateness.

2.3.2. Data collection—Semi-structured interviews ($n = 29$) were conducted with parent(s) who endorsed that: (a) their child had an anxiety score above the clinical cutoff on the SCARED-5 item and (b) anxiety symptoms were associated with impairment at home, school, with friends or family. Interviews lasted between 1 and 2 h in duration and most were audio recorded and transcribed verbatim by study staff. Most interviews were audiotaped ($n = 26$), however some parents ($n = 3$) stated they did not feel comfortable with audio-taping. For interviews that were not audio recorded, detailed notes were taken by the interviewer during the interview, and content was included in the coding process. An independent research assistant listened to each of the audio recordings while reading the transcript to check for accuracy. Transcriptions and notes were entered into NVivo qualitative software (Fraser, 2000), which was used to facilitate data management. After every 4–5 interviews, the research team debriefed to discuss observations and potentially sensitive information. Concept saturation was determined by a review of the data and ongoing discussion within the research team. After approximately 20 interviews, the research team noted significant repetition in ideas and concepts, and determined that concept saturation had been met (Guest, Bunce, & Johnson, 2006).

2.3.3. Data coding and analysis—This study utilized a data-transformation variant of the convergent parallel MMR design (Creswell & Plano Clark, 2011). This design was selected because of the limited understanding of parent's beliefs about child anxiety and the impact of these beliefs on mental health service utilization in existing literature. Moreover, this design allows for the qualitative data to be quantified and the quantitative data to be emphasized in the analysis and results (p. 81, Creswell & Plano Clark, 2011), which was necessary to best interpret the findings related to the complexities of parent's perceptions of stigma involving their children's anxiety disorder (Creswell & Plano Clark, 2011).

Coding of parent interviews was done by trained research staff using a coding, comparison, and consensus method outlined by Willms, Johnson, and White (1992) rooted in a grounded theory approach (Glaser & Strauss, 1967). Such an approach allows for themes to emerge from the data rather than from preconceived theories or concepts. Two coders (DC and BB) independently read through each transcript and coded six transcripts to generate an initial codebook. Subsequently, all data were double coded. Coders met to discuss inconsistencies and to reach consensus on discrepant codes in the presence of a third senior member of the study staff. At times, coding disagreements resulted in changes to the codebook, and previously coded transcripts were recoded using the most recent coding manual in order to reflect these changes. Periodically through data coding and codebook development, senior members of the research team consulted with a qualitative expert (LP) to ensure quality of the methodology. As thematic saturation was reached and no new themes were emerging from the qualitative data, the coders used the coding manual to code all transcripts for use in analyses (Guest et al., 2006). Stigma was identified by when the respondents conveyed that there was something unfavorable or negative associated with mental health problems or with mental health services. Coders were informed to code stigma when such comments were made during the interview. The quantitative data was analyzed using descriptive statistics and chi-square analyses.

3. Results

Twenty-nine parents of children 8–12 years of age participated in qualitative interviews. Twenty-six (90%) of the parent participants were mothers (mean age = 41.3 years, $SD = 7.1$). Ethnicity/race of parents was: Non-Latino White ($n = 17$, 58.6%), Latino/Hispanic ($n = 10$, 34.5%), African-American/Black ($n = 2$, 6.9%). Half of the parent participants who were Latino/Hispanic were predominantly Spanish speaking.

3.1. Endorsement frequencies of stigma

A discussion of stigma was initiated by 12 (41.3%) of the 29 parent participants during the qualitative interviews. Overall, there were 40 statements related to stigma and service use for anxiety coded by the raters. The number of stigma references made by Non-Latino White parents was compared to references made by ethnic minorities including Latinos, African Americans and parents who identified with more than one ethnicity/race. In this comparison, 3 of 17 Non-Latino White parents (17.6%) made comments related to stigma, and 9 out of 12 ethnic minority parents (82.4%) made references to stigma. Using chi-square analyses, this difference was significant, $X^2(1, N = 29) = 7.32, p < 0.01$. When Latinos and Non-Latino Whites were compared, 7 of 10 Latino participants (70%) and 3 of 17 (17.6%) Non-Latino Whites referenced stigma $X^2(1, N = 27) = 5.33 p < 0.05$. Of the 12 participants who discussed stigma, 6 (50%) endorsed that their child had previously received services: 14.3% (1 of 7) of Latinos, 100% (3 of 3) of non-Latino Whites, and 100% (2 of 2) of African-American participants. Of the 17 participants who did not endorse stigma, 8 (47.1%) reported that their child had received services, including 100% (3 of 3) of Latinos and 35.7% (5 of 14) of non-Latino Whites.

3.2. Qualitative themes

The majority of participants who initiated a discussion about stigma usually did so in the context of discussing their perceptions of mental health treatment and lack of seeking treatment for their child. Three broad themes emerged related to stigma from the qualitative data analysis: 1) Parental Concern for Negative Consequences, 2) Parent Internalized Stigma about Mental Health Problems, and 3) Negative Associations with Mental Health Treatment.

Parental Concern for Negative Public Consequences—Many participants expressed concern about how a diagnosis, such as an anxiety disorder, may affect their children in the future. Specifically, parents reported that their child would be labeled, resulting in negative consequences. Perceived consequences of an anxiety disorder label included negative systematic consequences and negative social consequences. Negative systematic consequences involved being put in a special education class, that the anxiety disorder label would become part of the child's public record, and that the label would affect their child's ability to obtain future employment.

“I don't want the school involved. I don't want my son to be labeled in the school... being put in special classes because I know how he feels about some of the kids that are in special class...”

“I was afraid it would be on his record. Afraid it would show up when he is looking for a job later on.”

In fact, another parent discussed seeking psychiatric help outside of the school and medical systems in order to avoid negative consequences. *“I’m going to take her for testing and I want to do it through a Catholic charity. I didn’t want her testing or evaluations to be in her public records. I didn’t want them to follow her...”*

Negative social consequences involved teasing from peers. Parents reported consequences of a diagnostic label would be that their child would be teased if peers knew he/she had an anxiety disorder and/or received mental health treatment for it, or the child will feel bad about receiving treatment. For example, one parent stated,

“Oh you know how kids are, they’re very cruel...and kids will tease her, if she says ‘I’m on medication’ maybe her brother or sister may mention it...kids are very cruel. You know how that is. They’ll...like I said she’s very sensitive.”

3.2.1. Parent’s Internalized Stigma about Mental Health Problems—Many parents expressed grief and concern about the significance of their child having a mental health problem. For example, parents stated that their child would not be considered “normal” if they had a diagnostic label, such as an anxiety disorder, or if they received mental health services. One parent stated, *“It was hard. It was hard for me to admit that... you know... something was wrong with him.”* Some parents noted general concerns that their child would “feel bad” if he/she was taken to counseling. For example, one parent stated, *“...the kids might say, might ask, ‘well, why are you going to counseling? ...and then he feels bad.”* But when asked if the child has ever expressed this worry, the parent stated, *“No, he never. I think it’s my worries. I think it’s just myself.”* Similar statements included:

“...And he actually doesn’t know that we’re doing this because if he notices, if he knows that we are talking to a psychologist or something like the... ‘oh my god you think I’m crazy’ or something.”

“Well my mom knew and my dad knew, my sister knew...I don’t think I would have had concerns but I think that my daughter would have and I think she didn’t want people to think she was weird.”

Other parents made more general statements associating seeking treatments with being crazy, *“they say to go to a psychiatrist, one is crazy”* and similarly, *“if you go to a psychologist, you must be crazy.”*

3.2.2. Negative Associations with Mental Health Treatment—Negative associations were made with specific mental health treatments for anxiety disorders. Specifically, parents viewed taking psychiatric medications negatively. In fact, parents frequently cited this negative perception as a reason for not seeking treatment for their child’s anxiety symptoms. Parents reported that they were concerned about the side effects of psychiatric medications and the potential for addiction. One parent stated, *“Medications is not necessary, he doesn’t need it, there is more that can be done. We avoid it out of fear of him becoming addicted to*

taking medications.” Another parent stated, “The longer he is on the medicine the more damage or chances that he could become a substance abuser in the future.”

Interestingly, parents from ethnic minority backgrounds expressed additional cultural stigma associated with psychiatric medication use. As one parent stated,

“...it's a cultural thing as well, but it's cultural coming from, coming from generations back like...my grandmothers and my great grandmothers, don't believe in, you...you don't need to give these kids medications to do this, and do that. You just need to be more disciplined... You don't, this medication was never something that when growing up I always heard that, even as an adult, you know, you don't give your kids medication... Who puts their kids on all these medications making them zombies.”

While most parents had positive perspectives about seeking counseling interventions, not all opinions were favorable. One parent stated:

“I like to go to the doctor experience, but not so much, if I have to go and get my head picked, you know what I mean.” While another parent made reference to a popular movie that focused on mental illness, *“I saw ‘The one that flew over the cuckoo's nest.’ I don't want those people, I don't want [them] to be around me personally and I would be fearful of being in that environment.”*

3.3. Racial/ethnic differences in themes

In general there was a low base rate of non-Latino Whites who endorsed stigma related concerns (i.e., 3 participants). Those that did report stigma referenced concerns mostly about medication, and previous negative experiences with service use. All three non-Latino White parents who endorsed stigma still sought and received services. Latinos, on the other hand, had higher rates of parent reported stigma and more varied expressions of stigma, which included concerns about being labeled, concerns about mental health service use being a part of one's record, and frequent citations relating mental health service use with being “crazy.” At least 3 of the 7 Latino parents who endorsed stigma made a comment relating to being “crazy” with mental health treatment. Interestingly, only 1 of 7 Latino parents who endorsed stigma reported seeking services.

4. Discussion

Previous findings support the presence of stigma among children with externalizing problems such as conduct disorders, substance abuse, and ADHD (Mukolo et al., 2010). However, this study is the first to examine stigma related beliefs among parents of children with significant anxiety symptoms through a data-transformation variant of convergent parallel mixed methods research (qual + QUAN). Although anxiety is often perceived as a less severe and impairing childhood disorder, almost half of parents mentioned stigma when discussing child anxiety and factors that inhibited appropriate service utilization. This is consistent with previous studies where approximately 40% of adults endorsed stigma associated with child mental health problems such as ADHD and depression. Additionally, the dimensions of stigma discussed in this study corresponded with previous

conceptualizations of stigma which have included concerns about: 1) labeling; 2) attaching a negative evaluation to the label (stereotypes); 3) using labels to create an “us” vs. “them” dichotomy; and 4) discrimination and loss of status that occurs because of labeling (Link & Phelan, 2001). In this study, parents seem to be most concerned with the potential negative consequences associated with having a psychiatric diagnostic label, such as child anxiety, and seeking mental health services; consequences included concerns about teasing, loss of status (e.g., being put in special education classes), and discrimination at school and in future employment. Parents also were concerned with stereotypes associated with having a mental health problem or seeking mental health services, including concerns about being perceived as “not normal” or “crazy.” The degree to which a person has internalized societally endorsed stigmatizing beliefs, such as negative stereotypes, about mental illness has been referred to as internalized stigma (Lysaker, P. H., Roe, D., & Yanos, P. T., 2007). **Parent internalized stigma** may play an important role in understanding caregiver burden as well as help-seeking behavior for children with mental health problems (Hasson-Ohayon, I., Levy, I., Kravetz, S., Vollanski-Narkis, A., & Roe, D., 2011). More research is necessary to further understand these stigma dimensions and their impact on child mental health and service access and utilization.

While stigma was associated with both seeking therapy/counseling and medication, parents noted more concerns with regard to medication. These findings are consistent with previous studies of parental attitudes toward medication for children with ADHD and anxiety disorders (Tarnowski, Simonian, Bekeny, & Park, 1992). For example, in a study focused on child social anxiety disorder (Chavira, Stein, Bailey, & Stein, 2003), parents reported more favorable attitudes toward counseling than pharmacotherapy; less favorable attitudes toward medication seemed mostly accounted for by concerns about side effects. In studies with adults, medication use has been associated with perceptions of being more severely ill, being weak or unable to handle one's problems, and being subjected to the negative effects of drugs (e.g., addiction) (Interian, Martinez, Guarnaccia, Vega, & Escobar, 2007; Olfson, Marcus, Tedeschi, & Wan, 2006; Sirey, Bruce, Alexopoulos, Perlick, Friedman, et al., 2001; Sirey, Bruce, Alexopoulos, Perlick, Raue, et al., 2001). In the NSS-C, the majority of participants believed that psychiatric medications affect a child's development (68%), give the child a flat, zombie-like affect (53%), and delay solving “real” behavior-related problems (66%) (Pescosolido et al., 2007). Thus, the emergent theme, **Negative Associations with Mental Health Treatment**, is consistent with this previous literature.

The degree to which stigmatized beliefs deter appropriate service access and use warrants further examination. Among those who reported concerns about stigma, half of parents still reported seeking mental health services, although preliminary evidence suggests that rates of service use were lower among Latinos with self-reported stigmatized beliefs. Conversely, among parents who did not report any stigma, half of parents also had received mental health services, however in this case all of the Latinos in this group had received mental health services. These findings are consistent with recent survey studies of caregivers, where stigma was associated with a lower parent-reported likelihood of help seeking for Latino parents, but not for non-Latino White or African American parents (Turner et al., 2015). Further review of the themes across ethnic groups revealed that Latinos more often endorsed

Parent Internalized Stigma, such as believing that their child would be perceived as “crazy,” and seeing this as a deterrent to seeking mental health treatment. At present, little research has examined the *meaning* of these stigmatizing terms (e.g., “crazy”), the weight they carry across cultures, and the impact of culture on mental health stigma (Abdullah & Brown, 2011). Additional research is necessary to examine whether specific dimensions of stigma differentially deter appropriate help seeking among families from diverse ethnic/racial groups.

Limitations of the study include the small sample size. Also, participants who agreed to be interviewed were willing to discuss their child’s anxiety symptoms, a factor that may be associated with more positive attitudes toward psychiatric disorders and mental health treatment. However, despite the potential selection bias, over 40% of participants endorsed stigma concerns—a number that is consistent with previous literature. Additionally, while the sample was selected based on a well-established screening measure for child anxiety and endorsement of impairment, participants were not formally diagnosed using a diagnostic interview. It may be that some of the children in the sample would not have met criteria for an anxiety disorder when using a standardized diagnostic protocol. Moreover, it is possible that perceptions of stigma may have been greater among children who had more significant impairment related to their symptoms of anxiety. Further, the sample was composed of parents who were mostly college educated and from middle socioeconomic status. Previous studies have suggested that stigma may have a greater impact on lower income and less educated families (Leaf, Bruce, & Tischler, 1986); thus, the generalizability of these findings to other populations awaits further research.

5. Conclusions

As of present, little research has focused on parent-reported stigma among children with anxiety disorders and how it affects mental health service access and utilization (Mukolo et al., 2010). Given the important role of parents as “gateway providers” to mental health services for their children, stigma is an important factor for many parents deciding to access services for their children with anxiety symptoms, and results suggest that this is an even more influential factor for Latino parents. Given that stigma can be pervasive, highly influential on help-seeking behaviors, and negatively related to mental health service use (Hinshaw, 2005; Mukolo et al., 2010; Woodward, Dwinell, & Arons, 1992), there is a clear need to address and modify such negative attitudes at various stages of service use. Findings underscore the need for practitioners to be aware of varying dimensions of stigma that may act as a barrier to mental health service utilization for varying types of childhood disorders, beyond those for children perceived as seriously mentally ill.

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