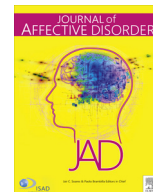




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## Journal of Affective Disorders

journal homepage: [www.elsevier.com/locate/jad](http://www.elsevier.com/locate/jad)

Research paper

## Barriers to access and participation in community mental health treatment for anxious children

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## ARTICLE INFO

## Article history:

Received 18 September 2015

Received in revised form

1 December 2015

Accepted 7 February 2016

Available online 10 February 2016

## Keywords:

Barriers to treatment

Children

Anxiety

Mental health

Computer-assisted cognitive-behavioral therapy

## ABSTRACT

**Background:** Anxiety disorders are the most common psychiatric disorders among children in the United States; yet many children do not receive treatment due to barriers to treatment access and participation. This study examined common barriers to treatment access and participation among anxious children who participated in computer-assisted cognitive behavioral therapy. Differences in barriers reported by treatment completers/non-completers were examined, as was the association with sociodemographic characteristics, anxiety severity, and impairment. The impact of barriers on treatment response was assessed, as well as the relationship with treatment expectancy and satisfaction.

**Method:** Barriers to access and participation, demographics, anxiety severity/impairment, treatment credibility and satisfaction were assessed among parents and children with anxiety ( $N=100$ ; ages 7–13) who were enrolled in a community-based randomized clinical trial.

**Results:** The most common access barrier was parents not knowing where or from whom to seek services (66%). Differences among completers and non-completers were related to stigma, confidentiality, and costs. The most common parent-reported barrier to participating was stress (32.4%) and child-reported barrier to participation was not having enough time to complete homework (22.1%). Of the sociodemographic, clinical and treatment characteristics, minority status, satisfaction, and treatment response were associated with barriers to treatment participation, although these associations varied by barriers related to treatment and external factors.

**Limitations:** Cross sectional design and lack of well-established psychometric properties for barriers measures were limitations.

**Conclusion:** Findings suggest that accessible, time-efficient, cost-effective service delivery methods that minimize stigma and maximize engagement when delivering evidence-based treatment for pediatric anxiety are needed.

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## 1. Introduction

Understanding treatment barriers for children with mental health needs is critical, especially for children with anxiety disorders since these are the most common psychiatric conditions affecting youth (Merikangas et al., 2010). Pediatric anxiety can

cause considerable suffering and impairment in children (Beesdo et al., 2009), and frequently persists into adulthood, increasing the likelihood of negative outcomes later in life (e.g., depression, substance abuse; Benjamin et al., 2013; Kendall et al., 2004). Despite the development of evidence-based practices (EBP) for childhood anxiety (Silverman et al., 2008), only 17.8% of children with an anxiety disorder receive treatment in the United States (Merikangas et al., 2011). Barriers to accessing effective treatments and barriers that affect youth and parent participation in treatment can delay or prevent children from receiving much needed

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mental health care. Identifying barriers that affect treatment access and participation among parents of children with anxiety disorders may help provide guidance on how to improve strategies for service utilization, treatment dissemination and implementation efforts for this population.

There are many reasons why parents may not access mental health treatment for their child (Kazdin, 2000; Kazdin et al., 1997), both tangible (e.g., logistical, cost, difficulty identifying a suitable service) and intangible (e.g., attitudes about treatment, urgency of the child's problem, stigma, motivation). In a study of parents of seventh-grade children who indicated that their child needed mental health services, the most commonly endorsed barriers to accessing treatment were parents not thinking the child's problem was serious (20.7%), wanting to solve the child's problem on their own (17.2%), and not knowing where to go (15.5%; Owens et al., 2002). About 10% of this sample also indicated barriers relating to cost, lack of confidence in recommended providers, not being recommended help by those they trusted, and the child not wanting to go to therapy. Perceptions about the severity and urgency of the child's problem may influence how motivated parents are to overcome other logistical obstacles to access care, with parents who perceived their child's problem to be more serious more likely to access services (Teagle, 2002). However, when intangible barriers (e.g., stigma, poor perceptions of treatment) are significant, parents may be less likely to access treatment (Larson et al., 2013). Despite anxiety being one of the most common mental health issues in childhood, there has been surprisingly little research examining barriers to accessing treatment. Given low service utilization amongst this population (Merikangas et al., 2011), there is a clear need to examine and address treatment access barriers for this population.

Even if parents and children are able to access treatment, there may be additional barriers that impact their continued treatment participation. Psychological treatments are often time-consuming and require ongoing participation and effort by the child and parent to ensure progress. Treatment-related variables, such as a poor relationship between the therapist and parent and/or child, may lead to families dropping out of treatment prematurely (de Haan et al., 2013; Stevens et al., 2006). Similarly, families who do not perceive the treatment to be relevant or credible may be more likely to discontinue treatment (Lewin et al., 2011; Wergeland et al., 2015). Conversely, barriers that affect treatment participation may also influence perceptions about treatment credibility and satisfaction and treatment outcome (Kazdin, 2000).

There are mixed findings in regards to the effect of socio-demographic characteristics and barriers to treatment participation. Some studies have suggested that low-income and racial/ethnic minority children are disadvantaged in regards to accessing effective mental health care due to treatment barriers (Alegria et al., 2010; Bringewatt and Gershoff, 2010; Young and Rabiner, 2015). Although Thurston and Phares (2008) found no racial differences in attitudes toward seeking services for their children between African American and Caucasian parents, African American parents experienced more barriers to treatment utilization (i.e., costs, limited service choices, having to travel too far). Owens et al. (2002) did not find any sociodemographic effects (e.g., child gender, child ethnicity, poverty, mother's age and education level) on parent-reported barriers to accessing mental health care; however, this may be reflective of their sample being primarily African American (82%), with more than half living in poverty (59%).

Given the range of barriers that can be encountered in traditional face-to-face treatment models, computer-based and computer-assisted treatments have been developed as one approach to overcome some of the barriers to treatment participation (e.g., Ebert et al., 2015). Results from pilot studies on a computer-based treatment for pediatric anxiety (e.g., *Cool Teens*) suggest potential

barriers to youth participation are finding time to complete the modules, being bored, not wanting to practice therapy tasks, having to disclose too much personal information, not having enough therapist support, not understanding the tasks, and losing interest (Cunningham et al., 2006; Cunningham and Wuthrich, 2008; Wuthrich et al., 2012). In a small open pilot trial of a computer-assisted program for children with anxiety, Camp-Cope-A-Lot (CCAL; Khanna and Kendall, 2010), two of six children thought the program was boring, two lost interest coming to sessions, and two children endorsed that they thought the program was too long. Encouragingly, in another open trial with 6 children receiving CCAL, all of the children felt supported by the therapist and other potential barriers (e.g., homework time, technical problems, understanding tasks and information, treatment relevance, time for practicing) were infrequently endorsed (Salloum et al., 2015). The current study expands the knowledge from these pilot studies of computer-assisted cognitive behavioral therapy (CBT) by examining feedback on treatment participation barriers in a much larger sample of anxious children treated with CCAL.

The aims of the current study were to examine: (1a) parents' perceptions of barriers they encountered to access treatment for their child with anxiety, and (1b) to compare whether those who dropped out of treatment were more likely to endorse specific access barriers than those who completed treatment; (2) parent and child perceptions of barriers to treatment participation amongst families who received CCAL; (3) associations between parents' perception of barriers to treatment participation and sociodemographic characteristics, anxiety severity and impairment, as well as the relationship with treatment expectancy and satisfaction; and (4) whether barriers to treatment participation were associated with treatment response.

## 2. Method

### 2.1. Participants

Children (aged 7–13) were recruited from three community outpatient mental health clinics located throughout Florida (Panhandle, Central Coast, and Southeastern Florida) to participate in a randomized clinical trial comparing CCAL to a treatment as usual (TAU; Storch et al., 2015). After TAU children were offered CCAL. As previously reported (Storch et al., 2015), inclusion criteria was a primary anxiety diagnosis (e.g., separation anxiety, generalized anxiety, specific phobia, or panic disorder) based upon a clinical interview with the child and parent. Baseline data from this study has been reported in unrelated studies (Hamblin et al., 2015; Johnco et al., 2015a, 2015b, in press, 2015c). The most common primary disorders were generalized anxiety (40%), social phobia (26%), separation anxiety (24%), specific phobia (9%), and panic disorder (1%). Children were excluded if they were receiving concurrent counseling for anxiety, had recently initiated antidepressant or antipsychotic medication, were actively suicidal or psychotic, or had a diagnosis of bipolar disorder or autism (Storch et al., 2015). The study sample consisted of 100 children and their parents. Demographic information is presented in Table 1 for the 100 children who completed the baseline assessment and 85 who received CCAL either immediately or after completion of a TAU period.

### 2.2. Procedures

This study was approved by the relevant Institutional Review Board. Parents were recruited to participate when they called one of the community clinics seeking services. Parents provided written informed consent and children provided assent. A trained

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