Journal of Anxiety Disorders 34 (2015) 94–99

Contents lists available at ScienceDirect

Journal of Anxiety Disorders

Preliminary study of family accommodation in youth with autism spectrum disorders and anxiety: Incidence, clinical correlates, and behavioral treatment response

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ARTICLE INFO

Article history:
Received 6 March 2015
Received in revised form 16 June 2015
Accepted 21 June 2015
Available online 8 July 2015

Keywords:
Anxiety
Autism spectrum disorder
Family accommodation
Cognitive-behavioral therapy

ABSTRACT

Anxiety symptoms are common in youth with autism spectrum disorders (ASD) and directly associated with symptom severity and functional impairment. Family accommodation occurs frequently among individuals with obsessive-compulsive and anxiety disorders; to date, no data exist on the nature and correlates of family accommodation in youth with ASD and anxiety, as well as its relationship to cognitive-behavioral therapy outcome. Forty children with ASD and a comorbid anxiety disorder participated. Clinicians administered measures of ASD and anxiety disorder caseness, anxiety symptom severity, and family accommodation; parents completed questionnaires assessing social responsiveness, internalizing and externalizing behaviors, and functional impairment. A subsample of youth ($n = 24$) completed a course of cognitive-behavioral therapy. Family accommodation was common and positively correlated with anxiety symptom severity, but not functional impairment, general internalizing symptoms, externalizing behavior, or social responsiveness. Family accommodation decreased following cognitive-behavioral therapy with decreases in family accommodation being associated with decreases in anxiety levels. Treatment responders reported lower family accommodation frequency and lower parent impact relative to non-responders. Clinical implications of this study in assessing and psychotherapeutically treating youth with ASD and comorbid anxiety are discussed.

Anxiety is common in children and adolescents with autism spectrum disorders (ASD) with estimates suggesting approximately 50% of youth meet clinically diagnostic criteria (Leyfer, Folstein, & Bacalman, 2006; Simonoff et al., 2008). Anxiety in youth with ASD can lead to compounded social deficits and impairments in daily living abilities and social relationships (Bellini, 2004; Drahota, Wood, Sze, & Van Dyke, 2011; Sukhodolsky et al., 2008). For this reason, there has been considerable interest in identifying efficacious treatments for anxious youth with ASD, with evidence consistently supporting the utility of cognitive-behavioral therapies (McNally, Lincoln, Brown, & Chavira, 2013; Reaven, Blakeley-Smith, Culhane-Shelburne, & Hepburn, 2012; Storch et al., 2013; Wood et al., 2009). Although empirical data are currently lacking on predictors of treatment outcome, clinical experience suggests that certain factors (e.g., comorbidity, family variables, symptom severity, child insight) may attenuate treatment response and be associated with a more severe clinical presentation and course. One factor that is associated with clinical presentation and treatment response in typically developing anxious youth is family accommodation, defined as behaviors on the part of family members that aim at preventing the child from experiencing distress/anxiety or having an anger outburst in response to actual or anticipated exposure to an anxiogenic trigger (Lebowitz & Bloch, 2012). Common examples of family accommodation include changing family plans or routines to accommodate the anxious child, providing reassurance and, among children

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http://dx.doi.org/10.1016/j.janxdis.2015.06.007
0887-6185/

with obsessive-compulsive disorder (OCD), involvement of family members in compulsions/rituals. There is evidence pointing to the importance of family accommodation in both the course of anxiety disorders as well as their treatment (Lebowitz & Bloch, 2012). Notably, family accommodation counters the goals of cognitive-behavioral treatment (CBT) by reinforcing the child's avoidance of feared situations, thus maintaining anxiety symptoms while compounding child and family impairment.

To date, most research on family accommodation has involved samples of adults and children with OCD, with recent investigations examining typically developing anxious children. No studies have examined the prevalence, correlates, and treatment implications of family accommodation in children with ASD and anxiety. Among individuals with OCD who are typically developing, accommodation is quite common in families of children and adults, with incidence rates up to 100% and 89%, respectively (Albert et al., 2010; Peris et al., 2008; Storch, Geffken, & Merlo, 2007). Family accommodation is directly associated with obsessive-compulsive symptom severity and functional impairment (Caporino et al., 2012; Flessner et al., 2011; Merlo, Lehmkuhl, Geffken, & Storch, 2009; Storch et al., 2007; Storch, Larson, & Muroff, 2010), and mediates the relationship between symptom severity and functional impairment (Bipeta, Yerramilli, Pingali, Karredla, & Ali, 2013; Caporino et al., 2012; Storch et al., 2007). Several studies have found that family accommodation is directly associated with internalizing and externalizing symptoms (Lebowitz, Omer, & Leckman, 2011; McGuire et al., 2013; Storch et al., 2007; Storch, Jones, & Lack, 2012), while parental anxiety has been linked to increased family accommodation (Caporino et al., 2012; Flessner et al., 2011; Peris et al., 2008). Family accommodation decreases following CBT (Barrett, Healy-Farrell, & March, 2004; Ferrao et al., 2006; Merlo et al., 2009) and lower baseline levels of family accommodation and greater decreases in family accommodation following treatment are associated with better treatment outcomes (Garcia et al., 2010; Merlo et al., 2009). Specifically, changes in family accommodation following CBT are associated with post-treatment symptom severity and impairment (Merlo et al., 2009).

When compared to those with OCD, family accommodation has been studied less extensively in families of youth with anxiety disorders. As in youth with OCD, family accommodation is common in children with anxiety disorders, with incidence rates reaching 97% (Lebowitz et al., 2013; Thompson-Hollands, Kerns, Pincus, & Comer, 2014). Frequently endorsed accommodating behaviors include providing reassurance, participating in symptoms, and modifying routines and schedules (Lebowitz, Scharfstein, & Jones, 2014). Parents reported experiencing distress related to accommodation and negative consequences, such as exacerbation of the child's distress/anxiety and anger outbursts when accommodation was not provided (Lebowitz et al., 2014, 2013). Similar to findings in youth with OCD, family accommodation was associated with worse anxiety symptom severity and family functioning among youth with anxiety disorders (Lebowitz et al., 2014, 2013; Thompson-Hollands et al., 2014). Maternal distress was linked to increased family accommodation (Thompson-Hollands et al., 2014). No data have been published examining family accommodation as a predictor of treatment outcome in anxious youth.

Given the clinical implications of family accommodation and that clinical experience suggests that it occurs with frequency in youth with ASD and anxiety, it is important to examine the nature and correlates of family accommodation in families of children with anxiety and ASD and the extent to which it plays a role in treatment outcomes. We had four study aims. First, we examined the phenomenology of family accommodation in this population and expected that family accommodation would occur frequently in families of children with ASD and anxiety, similar to rates in youth with either OCD or anxiety. Second, we examined correlates of family accommodation, specifically anxiety symptom severity, functional impairment, internalizing and externalizing problems, and ASD-related social functioning. Based on previous research with families of children with OCD and anxiety (e.g., Caporino et al., 2012; Lebowitz et al., 2013; Storch et al., 2007; Thompson-Hollands et al., 2014), we expected that family accommodation would be positively related to all of these variables. Although no data exist with regards to ASD-related social functioning, we expected to find a direct association in that families would be more likely to accommodate anxiety symptoms among youth with more significant social impairments. Finally, we examined the relationship between family accommodation and CBT outcome. We expected that family accommodation would decrease after CBT participation, and that post-treatment family accommodation levels would be related to treatment response.

1. Method

Participants included 40 children ($n = 33$; 82.5% males) and their parent, who were being screened for inclusion in one of three psychosocial treatment studies for anxiety (Storch et al., 2013, 2015). All participants were diagnosed with Autistic Disorder, Asperger's Syndrome, or Pervasive Developmental Disorder NOS (PDD NOS) consistent with the Diagnostic and Statistical Manual Fourth Edition Text Revision (DSM-IV-TR) (APA, 2000) and exhibited clinically significant anxiety as evidenced by the Anxiety Disorders Interview Schedule–Child and Parent Versions (ADIS-IV-C/P; Silverman & Albano, 1996) and Pediatric Anxiety Rating Scale (PARS; RUPP, 2002). Autism spectrum diagnoses were established using the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999), administered by a certified rater, and the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), and were confirmed through records review and discussion of case material by a second licensed clinician. Exclusion criteria included recent changes to psychiatric medications (if applicable), presence of suicidality, and evidence of current/past psychosis or mania.

1.1. Measures

1.1.1. ADIS-IV-C/P (Silverman & Albano, 1996)

The ADIS-IV-C/P are psychometrically-sound (Silverman, Saavedra, & Pina, 2001) semi-structured clinician administered interviews given to the parent and child individually to capture a range of anxiety and comorbid disorders. A final list of diagnoses and yoked severity ratings ranging from 0 (not at all) to 8 (very much) are made by the clinician based on parent and child report, as well as clinical judgment. The ADIS-IV-C/P was completed at the pre-treatment assessment.

1.1.2. PARS (RUPP, 2002)

The PARS is a clinician-administered measure used to assess for the presence and severity of anxiety symptoms using a Symptom Checklist and Severity Scale. The Severity Scale is comprised of the following five items on a 0 (none) to 5 (extreme) Likert scale: Symptom Frequency, Distress, Avoidance, Home Interference, and Other Interference (e.g., peer relationships, school functioning).[1] Strong psychometric properties have been reported in children

[1] RUPP (2002) reported on a five-item PARS Severity Score that excluded items assessing the number of anxiety symptoms and physical symptoms. Walkup et al. (2008) reported psychometric data on a six-item PARS Severity Score that includes the physical symptoms item. Given that psychometric data on the PARS in youth with ASD exists using the five-item Severity Score (Storch, Wood, et al., 2012), we chose to use the five-item PARS Severity Score.