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Family Accommodation in Autism Spectrum Disorder

Judah Koller[1] and Eli R. Lebowitz[2]
[1]Seymour Fox School of Education, The Hebrew University of Jerusalem, Jerusalem, Israel
[2]Yale School of Medicine, Child Study Center, Yale University, New Haven, CT, USA

Definition

Ways in which family members, mostly parents, modify their behavior to help a child avoid or alleviate distress and negative affect associated with mental health problems (Lebowitz and Bloch 2012; Lebowitz et al. 2014).

Historical Background

A sizable body of literature indicates that family accommodation is common among families of children with obsessive-compulsive disorders (OCD) and anxiety disorders. Such accommodation is associated with both proximal and distal negative outcomes. High levels of family accommodation in these populations are associated with increased severity of anxiety or OCD symptoms, poorer psychosocial functioning, and elevated parental distress (Caporino et al. 2012; Lebowitz and Bloch 2012; Lebowitz et al. 2013, 2014; Storch et al. 2007). Additionally, higher levels of family accommodation are predictive of poorer subsequent response to treatment in children with OCD and anxiety disorders (Lebowitz et al. 2016; Kagan et al. 2016). These findings have already yielded clinical benefit through the development of an efficacious parent-based intervention that targets the reduction of family accommodation (Lebowitz et al. in press). This work raises the possibility that the study of family accommodation in children with other disorders could yield similar contributions.

Several findings point to a partial phenotypic overlap between autism spectrum disorders (ASD), OCD, and anxiety disorders, in addition to a possible partial overlap in their etiology. The phenotypic overlap exists with regard to the restricted and repetitive behaviors (RRBs) inherent to a diagnosis of ASD. RRBs are defined in the *Diagnostic and Statistical Manual of Mental Disorders* 5 (DSM5) (APA 2013) as "restricted, repetitive patterns of behavior, interests, or activities…" Within OCD, compulsions are defined as "repetitive behaviors or mental acts." While not synonymous, these two concepts bear resemblance to one another (Jacob et al. 2009; Wood and Gadow 2010). In addition to the partial phenotypic overlap, high comorbidity between these diagnostic constructs has been noted, with greater prevalence of anxiety disorders and OCD in children with ASD than in typically developing children (van Steensel et al. 2011). Children of parents with OCD or ASD are at greater risk of ASD or OCD, respectively (Meier et al. 2015),

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and the likelihood that an individual will be diagnosed with OCD or anxiety disorders is elevated in relatives of children with ASD (Jacob et al. 2009), pointing to some degree of shared heritability.

Given the above-noted links between OCD, anxiety disorders, and the RRBs of children with ASD, as well as the potential biological links between the disorders, an examination of family accommodation in the context of autism, specifically regarding RRBs, was undertaken.

Current Knowledge

Building on the data related to family accommodation in OCD and anxiety disorders, an examination of family accommodation in the context of RRBs in ASD was deemed worthwhile (Feldman et al. 2019). Applying the concept of accommodation to RRBs, however, is complicated by several factors. Research has suggested the existence of different sub-groups of RRBs, including repetitive motor and sensory behavior, insistence on sameness, ritualistic behavior, compulsive behavior, circumscribed interests, and self-injurious behavior (Honey et al. 2012; Leekam et al. 2011). Notably, different types of RRBs have been linked to different psychiatric symptoms (e.g., anxiety, depression, and oppositional-defiant symptoms; Lidstone et al. 2014; Stratis and Lecavalier 2013). These and other findings (e.g., Leekam et al. 2011) suggest that the various types of RRBs, and perhaps even different specific RRBs within a single sub-group, may differ in both their etiologies and functions.

Furthermore, RRBs may also vary in function and in degree of adaptiveness, indicating that accommodation of these RRBs may be either potentially helpful or detrimental to the child and family system. Certain RRBs may allow the individual to occupy themselves, regulate hyper- or hypo-sensory arousal, or reduce anxiety (Leekam et al. 2011). In some cases, these behaviors can even provide a source of income and employment (Attwood 2003; Howlin 2003). Other RRBs, however, such as self-injurious behaviors, are unambiguously harmful. Studies link certain types of RRBs, including preoccupation with object parts, sensory interests, and stereotyped motor behaviors, to poorer reasoning skills, lower adaptive functioning at a later age, and increased caregiver stress (Harrop et al. 2016; Troyb et al. 2016). Further complicating the matter, findings suggest that the same RRBs may have differing etiologies and serve different functions for different children (Leekam et al. 2011; Stratis and Lecavalier 2013).

Particularly relevant to the issue of family accommodation in the context of ASD is the role of RRBs in regulating arousal and in alleviating anxiety and distress, similar to the role of compulsive behaviors in OCD (Leekam et al. 2011; Lidstone et al. 2014). It has been proposed that family accommodation of children's OCD symptoms increases the severity of these symptoms over time by enabling avoidance of distress-inducing stimuli and hampering the development of more adaptive strategies for independent regulation of negative arousal (Lebowitz 2013; Storch et al. 2007). To the extent that RRBs might serve to alleviate distress in children with ASD, family accommodation of RRBs may function in a similar manner and could potentially lead to decreased self-regulation.

Prior to Feldman et al. (2019), limited work had been done examining the role of family accommodation in ASD. Russel et al. (2013) examined a small group of adolescents and adults ($n = 23$) with comorbid ASD and OCD who received cognitive behavioral therapy for OCD. In that study, higher reported family accommodation prior to treatment was associated with poorer response to the treatment. Storch et al. (2015) examined the prevalence and correlates of family accommodation of anxiety symptoms in 40 children with ASD and comorbid anxiety disorders. In line with previous findings on family accommodation in anxiety disorders, family accommodation of anxiety symptoms in the context of ASD was found to be highly prevalent and was correlated with the severity of the children's anxiety symptoms. The same study also found that family accommodation decreased following cognitive behavioral therapy, with the reduction in family accommodation associated with the

improvement in the children's anxiety symptoms. Of note, both of the aforementioned studies focused on accommodation of the anxiety or OCD symptoms and did not investigate accommodation of RRBs.

The first study to examine family accommodation of core ASD symptoms, specifically RRBs, piloted the use of the Family Accommodation Scale for Restricted and Repetitive Behaviors (FAS-RRB; Feldman et al. 2019). This study found that accommodation of RRBs is highly prevalent, with 80% of parents engaging in family accommodation at least once a month and 55% reporting daily accommodation. These rates of accommodation are high, but lower than those reported in pediatric OCD (Lebowitz et al. 2016) and anxiety disorders (Lebowitz et al. 2013, 2014, 2016; Thompson-Hollands et al. 2014), as well as those reported for anxiety symptoms in children with ASD (Storch et al. 2015). The most common accommodations of RRBs reported by parents of children with ASD were (1) providing symptom-related items, (2) participating in symptom-related actions, and (3) assisting in the avoidance of symptom-related stimuli. In this study, higher levels of accommodation were strongly associated with higher RRB severity ($r = 0.820, p < 0.001$). Additionally, higher levels of accommodation were associated with poorer communication ($r = -0.258, p = 0.029$) and daily living skills ($r = -0.407, p < 0.001$) in the children, and a majority of parents report feeling distress due to the accommodation. Most parents also reported their children responding aggressively when parents do not accommodate. These findings parallel previous work focused on children with OCD and anxiety disorders (Lebowitz et al. 2013, 2016; Thompson-Hollands et al. 2014).

While certain similarities exist between family accommodation of RRBs in ASD and accommodation of OCD and anxiety disorders, there are also significant differences. Every child with ASD presents with some RRBs. However, the frequency, severity, and nature of these behaviors vary widely. Some children with ASD experience difficulty primarily in the area of social communication and interaction while presenting with relatively few RRBs. In such cases, parents may have fewer RRBs to accommodate compared with cases in which the RRBs are a more prominent clinical feature. In the context of OCD and anxiety, the accommodation can relate to almost any clinical feature of the disorder. This may partially explain the lower rates of accommodation reported by parents of children with ASD relative to those reported in OCD and anxiety disorders. Additionally, in light of the heterogeneity in form and function of RRBs, it is yet to be determined whether a reduction of accommodation of RRBs would be invariably beneficial or whether clinical recommendations must be informed by a functional assessment of the child's symptoms.

Future Directions

Further research on the directions of associations and the causal links that may exist between accommodation and severity of ASD is required. RRB severity and lower adaptive functioning may lead to increased family accommodation. It is alternatively plausible that, as in OCD and anxiety disorders, family accommodation leads to more severe child symptomatology and to greater functional impairment in the children. A third possibility is that the relationship is bidirectional or moderated by variables not yet taken known. Longitudinal research is critically needed in order to address these questions.

An additional area worthy of attention is the motivation of parents engaging in family accommodation of RRBs. When asked to provide a qualitative description of their child's RRBs, some parents used language expressing a belief that these behaviors were not optional, such as "must" or "have to," in describing both the RRBs and their own accommodations. As such, parents of children with ASD may be providing accommodations due to their belief that no other alternatives exist. Children's aggressive responses to not being accommodated, reported by a majority of parents, are another likely contributor to the maintenance of such parental accommodations.

Family accommodation may offer a useful target for clinical interventions for individuals with ASD and their parents or families. Future work

elucidating the role of accommodation should aim to determine how best to support parents in this context. In both OCD and anxiety disorders, current interventions emphasize the supportive reduction of family accommodation as a path to increasing independent coping in the child (Lebowitz 2015; Kagan et al. 2016; Lebowitz et al. 2018a, b; Salloum et al. 2018). Recent work supports the efficacy of SPACE (Supportive Parenting for Anxious Childhood Emotions), a parent-based intervention that reduces family accommodation of childhood anxiety and OCD. In a recent randomized controlled trial, SPACE was as efficacious as CBT in treating child anxiety disorders, and it led to greater reduction in family accommodation (Lebowitz et al. 2019). A similar approach may be beneficial in cases of ASD. The development and evaluation of such an intervention program targeting the accommodation of RRBs would be novel and could represent an important step forward in autism-specific interventions.

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