



# Family Accommodation in Autism Spectrum Disorder

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## Abstract

Family accommodation occurs frequently among families of children with OCD and anxiety disorders, with higher levels of accommodation repeatedly associated with greater symptom severity, lower functioning, and poorer treatment outcomes for children. This is the first examination of family accommodation of restricted and repetitive behaviors (RRBs) in children with autism spectrum disorder (ASD). Parents of children with ASD (N = 86) completed questionnaires assessing their children's RRBs and parental accommodation of these symptoms. Most participants (80%) reported engaging in accommodation at least once a month and family accommodation was significantly positively correlated with RRB severity. These results suggest accommodation of RRBs follows a pattern similar to that reported in obsessive compulsive and anxiety disorders, and highlight avenues for potential parent-based interventions.

**Keywords** Autism spectrum disorder · Restricted and repetitive behaviors · Family accommodation · Parent–child interaction

Parent behavior plays a role in the presentation, course and response to treatment of numerous childhood psychopathologies (e.g., Ginsburg et al. 2005; Lebowitz et al. 2014b; McKee et al. 2008; Yap and Jorm 2015). Within obsessive–compulsive disorder (OCD) and across the anxiety disorders, much work has highlighted a particular form of parent behavior termed *family accommodation* (Calvocoressi et al. 1995; Lebowitz et al. 2016; Lebowitz et al. 2014b; Lebowitz et al. 2013). Family accommodation describes the ways in which family members, mostly parents, of children with emotional disorders modify their behavior to help their

child avoid or alleviate distress and negative affect caused by the disorder (Lebowitz and Bloch 2012; Lebowitz et al. 2014b).

Data indicate that family accommodation is common among families of children with OCD and anxiety disorders and that this pattern is associated with negative sequelae, both proximally and distally. High levels of family accommodation are associated with greater severity of anxiety or OCD symptoms (Caporino et al. 2012; Lebowitz et al. 2013, 2016; Lebowitz et al. 2014b; Storch et al. 2007), poorer psychosocial functioning (Caporino et al. 2012; Lebowitz and Bloch 2012; Storch et al. 2007), and elevated parental distress (Lebowitz et al. 2013; Lebowitz et al. 2014b). Moreover, high levels of family accommodation predict poor treatment outcomes in children with OCD and anxiety disorders (Lebowitz and Bloch 2012; Lebowitz et al. 2016; Kagan et al. 2016). These findings have already yielded clinical benefit through the development of efficacious parent-based interventions that target the reduction of family accommodation, and highlight the possibility that the study of family accommodation in children with other disorders could yield similar contributions.

Autism spectrum disorder (ASD) is a group of neurodevelopmental disorders characterized by persistent deficits in social communication and social interaction as well as the presence of restricted and repetitive behaviors and/or

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stereotyped interests (RRBs; APA 2013). Several findings indicate a degree of phenotypic overlap between ASD, OCD and anxiety disorders, in addition to possible partially shared etiology. Researchers have noted that the RRBs characteristic of ASD appear similar to the repetitive thoughts and actions characteristic of OCD (Jacob et al. 2009; Wood and Gadow 2010). In addition to the phenotypic overlap, high comorbidity has also been noted, with greater prevalence of anxiety disorders and OCD in children with ASD than in typically developing children (van Steensel et al. 2011). Furthermore, children of parents who were diagnosed with OCD or ASD were found to be at greater risk of ASD or OCD, respectively (Meier et al. 2015) and risk of OCD and anxiety disorders is elevated in relatives of children with ASD (Jacob et al. 2009), indicating a degree of shared heritability. In light of the commonalities between symptoms of OCD and anxiety disorders and the restricted and repetitive behaviors of children with ASD, as well as the data supporting a genetic link between the disorders, it is of interest to examine whether parental responses to these symptoms also share common characteristics.

Examining family accommodation of RRBs necessitates close consideration of the heterogeneity within this symptom category. Research has suggested the existence of different sub-groups of RRBs, such as 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 their etiologies and functions.

In addition to varying in form, RRBs may also vary in function and in degree of adaptiveness, making accommodation of the RRBs likewise of potential help or hindrance to different functions. For example, it has been suggested that RRBs may serve functions including occupying oneself, regulating hyper- or hypo-sensory arousal, and reducing anxiety or stress (Leekam et al. 2011). Some RRBs, such as self-injurious behaviors, are unambiguously detrimental. Others may be linked to negative outcomes, for instance, studies had found relations between certain types of RRBs, including preoccupation with object parts, sensory interests, and stereotyped motor behaviors, and poorer reasoning skills, lower adaptive functioning at a later age and increased caregiver stress (Harrop et al. 2016; Troyb et al. 2016). And yet other RRBs may be adaptive or beneficial, for example, by providing a source of enjoyment for individuals with ASD or, in some cases, a source of income and employment (Attwood 2003; Howlin 2003). Further complicating

the matter, findings suggest some RRBs may have differing etiologies and/or functions in children with a range of developmental and clinical profiles (Leekam et al. 2011; Stratis and Lecavalier 2013).

Particularly relevant to the issue of family accommodation, is the role of RRBs in regulating arousal, and 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 serve to alleviate distress in children with ASD, family accommodation of RRBs might function in similar manner, and could contribute to poorer independent regulation over time.

To date, no studies have reported on family accommodation of RRBs in youth with ASD, and only two studies have examined family accommodation of OCD or anxiety in youth with ASD. Russell et al. (2013) examined a small group of adolescents and adults ( $n=23$ ) with comorbid ASD and OCD who underwent cognitive-behavioral therapy for OCD. Higher family accommodation prior to treatment was linked to poorer treatment outcomes. Storch et al. (2015) examined the prevalence and correlates of family accommodation of anxiety symptoms in 40 children with ASD and comorbid anxiety disorders. Consistent with previous findings on family accommodation in anxiety disorders, family accommodation of anxiety symptoms was highly prevalent and its frequency and impact on parents and children positively correlated with the severity of the children's anxiety symptoms. The study also found that family accommodation was reduced following cognitive-behavioral therapy, with the reduction in family accommodation linked to improvement in the children's anxiety symptoms. Of note, both of these studies focused on accommodation of the anxiety or OCD symptoms and did not investigate accommodation of RRBs (Lebowitz et al. 2016).

Our study aimed to examine, for the first time, the presence and impact of family accommodation of RRBs among parents of children with ASD, and the relation between the degree of family accommodation and the severity of these behaviors. We hypothesized that the degree to which families accommodate their children's RRBs will correlate with the severity of these behaviors, and that this association will vary in strength across different types of RRBs. We also hypothesized that an association exists between family accommodation of RRBs and children's adaptive functioning skills. A secondary aim was to examine the internal consistency and factorial structure of a family accommodation scale adapted for measuring accommodation of RRBs.

## Method

### Participants

The study included 86 children between the ages of 1.7 and 16 years (22 females; mean age = 6.81, SD = 3.19) diagnosed at a tertiary autism center in a large medical center and their parents participated in the study. The clinic is mandated to conduct diagnostic assessments for children of various ages where the primary concern is ASD. While priority is given to children in need of an initial diagnosis, the public nature of the clinic indicates a wide range of age and clinical characteristics among the sample. All participants underwent comprehensive assessments including medical history, neurological examination, cognitive and adaptive behavior evaluations and diagnostic measures, including the Autism Diagnostic Observation Schedule 2 (ADOS2; Lord et al. 2012) and the Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994).

Out of 118 children, 32 were excluded from the study: nine were not diagnosed with ASD, and 23 were excluded due to missing data. Thirteen participants who did not complete items

1–7 of the FAS-RRB were excluded from correlation tests. Another participant who did not have data from the Vineland Adaptive Behavior Scale was excluded from correlation tests involving that scale (Table 1).

### Measures

#### Family Accommodation Scale for Restricted and Repetitive Behaviors

Parents completed the FAS-RRB, an adapted version of the family accommodation scales that have been used for research into family accommodation of OCD and anxiety symptoms (Calvocoressi et al. 1995; Lebowitz et al. 2013), aimed at assessing family accommodation of RRBs by parents of children with ASD. FAS-RRB comprises 11 items rated on a 5-point Likert-type scale ranging from 0 (never) to 4 (daily). Seven items assess frequency of accommodating behaviors (e.g., “How many times did you help your child avoid stimuli that relate to his/her repetitive behaviors?”). These seven items are summed to provide a total accommodation score. The additional four items include one item that relates to parental distress caused by the accommodation, and three items query short-term child consequences of not being accommodated (e.g., “Did the child respond aggressively when you did not help him/her?”).

#### Repetitive Behavior Scale-Revised (RBS-R; Bodfish et al. 1999)

Parents completed the RBS-R, a questionnaire aimed at assessing the frequency and severity of RRBs over the previous month. This questionnaire consists of 43 items which are rated on a four-point Likert scale ranging from 0 (behavior does not occur) to 3 (behavior occurs and is a severe problem). The RBS-R items divide into 6 subgroups of RRBs: stereotypic behavior, self-injurious behavior, compulsive behavior, ritualistic behavior, sameness behavior and restricted behavior. The RBS-R has been found to be a reliable measure of repetitive behaviors in ASD (Lam and Aman 2007; internal consistency: alpha ranging between .78 and .91; alpha in our sample = .951).

#### Autism Diagnostic Observation Schedule 2 (ADOS 2; Lord et al. 2012) and Autistic Diagnostic Interview Revised (ADI-R; Lord et al. 1994)

The ADOS 2, a semi-structured assessment of children’s communication, social, and play skills, and the ADI-R, a semi-structured interview for caregivers, were used to establish ASD diagnoses. These instruments have been found to be reliable and valid (Lecavalier et al. 2006a, b; Lord et al. 1994; Reszka et al. 2014).

**Table 1** Clinical characterization of the sample

|   |               |
|---|---------------|
| Age: mean ( <i>SD</i> )                   | 7.89 (3.19)   |
| Females: <i>N</i> (%)                     | 22 (25.58)    |
| ADOS Comparison Score: mean ( <i>SD</i> ) | 8.11 (1.77)   |
| <i>N</i>                                  | 83            |
| VABS 2                                    |               |
| Mean ( <i>SD</i> )                        |               |
| Communication                             | 80.86 (11.19) |
| Adaptive behavior                         | 75.21 (11.52) |
| Socialization                             | 68.85 (11.69) |
| Motor <sup>a</sup>                        | 82.83 (12.32) |
| Composite score                           | 72.92 (9.63)  |
| Verbal IQ: mean ( <i>SD</i> )             | 87.85 (16.55) |
| <i>N</i>                                  | 66            |
| FAS-RRB                                   |               |
| Mean ( <i>SD</i> )                        |               |
| Accommodation                             | 10.71 (9.18)  |
| Distress                                  | 1.6 (1.72)    |
| Consequences                              | 5.56 (4.76)   |
| RBS-R                                     |               |
| Mean ( <i>SD</i> )                        |               |
| Total score                               | 33.14 (23.88) |
| Stereotyped behaviors                     | 4.32 (3.89)   |
| Self-injurious behaviors                  | 2.59 (3.96)   |
| Compulsive behaviors                      | 5.19 (4.52)   |
| Ritualistic behaviors                     | 7.43 (5.05)   |
| Sameness behaviors                        | 9.82 (8.28)   |
| Restricted behaviors                      | 3.80 (2.86)   |

<sup>a</sup>Data available for participants under the age of 7 years (*n* = 54)

## Vineland Adaptive Behavior Scales 2 (VABS; Sparrow et al. 2005)

Parents completed the VABS, a reliable (Limperopoulos et al. 2006; Sparrow et al. 1984) instrument used to evaluate children's adaptive functioning in four domains: communication, daily living skills, socialization, and motor skills.

### Procedure

Participants completed all of the above-mentioned measures during their assessment. Participants were offered, but not required, to complete the FAS-RRB and RBS-R. An interdisciplinary team of experts trained in gold-standard diagnostic practice for ASD conducted all evaluations. The professionals who performed the ADI-R and ADOS-2 established reliability in these standardized tests as required.

### Data Analytic Plan

We performed bi-variate Pearson correlations to examine the associations between family accommodation scores (based on items 1–7 of FAS-RRB) and the RBS-R total and sub-scale scores, as well as with the Vineland 2 communication skills and daily living skills scores. Internal consistency on the FAS-RRB was assessed using Cronbach's  $\alpha$ . Correlations between family accommodation and sub-types of RRBs were compared using Lee and Preacher's (2013) software for the test of difference between two dependent correlations with one variable in common. Given the preliminary nature of this study and the relatively small sample relative to the number of analyses performed, we chose not to correct our  $\alpha$ , which was set as .05. Twenty out of 86 participants had missing items on the RBS-R (of them, 16 had 1–3 missing items, while 4 had 4–7 missing items). The missing items were imputed using the mean response to other items on the same subscale.

## Results

### Descriptive Data

Most participants ( $n = 69$ ; 80.23%) reported engaging in family accommodation of RRBs at least once a month. Of these, 48 (55.81%) reported daily accommodation of their child's RRBs, while 29 (33.72%) reported engaging in accommodation 3–6 times per week, and 37 (43.02%) 1–2 times per week. Forty-four parents (51.16%) reported feeling distress due to making these accommodations, and 56 (65.12%) reported an aggressive response by their child to not being accommodated.

The most frequently reported forms of accommodation were: participating in RRB-related actions (endorsed by 55

parents; 63.95%), assisting avoidance of RRB-related stimuli, and providing RRB-related items (both endorsed by 53 parents; 61.63%).

### Family Accommodation, RRB Severity, and Adaptive Behavior Skills

As presented in Table 2, family accommodation was significantly positively correlated with RRB severity, as measured by RBS-R ( $r = .820$ ,  $p < .001$ ,  $n = 73$ ). The self-injurious behavior scale had a significantly weaker correlation ( $r = .528$ ,  $p < .001$ ,  $n = 73$ ) with family accommodation than stereotyped ( $r = .721$ ,  $p < .001$ ,  $n = 73$ ;  $Z = -2.268$ ,  $p = .023$ ), compulsive ( $r = .710$ ,  $p < .001$ ,  $n = 73$ ;  $Z = -2.246$ ,  $p = .025$ ), ritualistic ( $r = .750$ ,  $p < .001$ ,  $n = 73$ ;  $Z = -2.601$ ,  $p = .009$ ) or sameness ( $r = .739$ ,  $p < .001$ ,  $n = 73$ ;  $Z = -2.648$ ,  $p = .008$ ) behavior. Self-injurious behavior did not differ significantly from restricted behaviors ( $r = .637$ ,  $p < .001$ ,  $n = 73$ ) in its correlation with family accommodation ( $Z = -1.189$ ,  $p = .234$ ). There were no significant differences in correlations with family accommodation between other RRB subscales ( $p > .05$ ). Additionally, family accommodation was significantly negatively correlated with adaptive behavior skills ( $r = -.407$ ,  $p < .001$ ,  $n = 72$ ) and communication skills ( $r = -.258$ ,  $p = .029$ ,  $n = 72$ ), as measured by VABS 2. Correlations between family accommodation and other study measures are summarized in Table 2 and Fig. 1 visualizes the association between family accommodation and RRB severity.

**Table 2** Correlation between FAS-RRB accommodation items and RBS-R scores and VABS 2 scores

|                          | FAS-RRB accommodation items |
|--------------------------|-----------------------------|
| RBS-R                    |                             |
| Total score              | .820 <sup>a</sup>           |
| Stereotyped behaviors    | .721 <sup>a</sup>           |
| Self-injurious behaviors | .528 <sup>a</sup>           |
| Compulsive behaviors     | .710 <sup>a</sup>           |
| Ritualistic behaviors    | .750 <sup>a</sup>           |
| Sameness behaviors       | .739 <sup>a</sup>           |
| Restricted behaviors     | .637 <sup>a</sup>           |
| VABS 2                   |                             |
| Communication            | -.258 <sup>b</sup>          |
| Adaptive behavior        | -.407 <sup>a</sup>          |

<sup>a</sup> $p < .001$

<sup>b</sup> $p = .029$

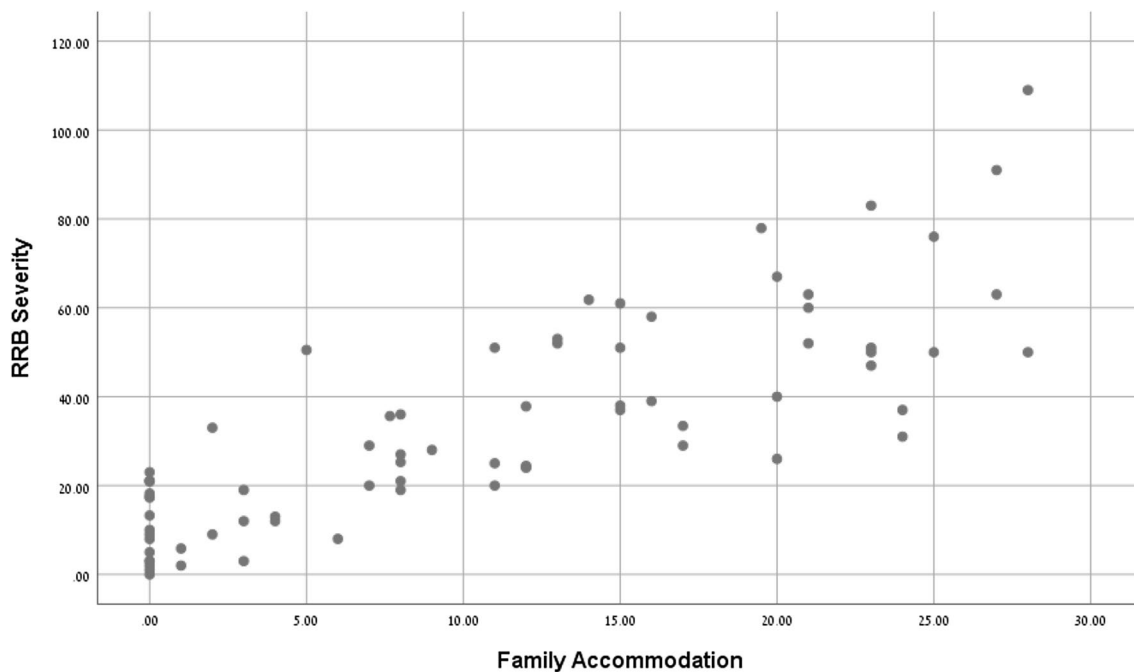


Fig. 1 Scatter plot of the relationship between the seven FAS-RRB accommodation items and RBS-R total scores

**FAS-RRB Internal Consistency and Factorial Structure**

The seven FAS-RRB accommodation items displayed high internal consistency, Cronbach’s  $\alpha = .935$ . Additionally, as this is the first test of the FAS-RRB, to account for

potential correlations between factors, rotated principal axis factor analysis (Varimax rotations) was conducted on the seven accommodation items. This analysis resulted in a single factor model, explaining 65.260% of the variance with an eigenvalue of 4.568 (Fig. 2).

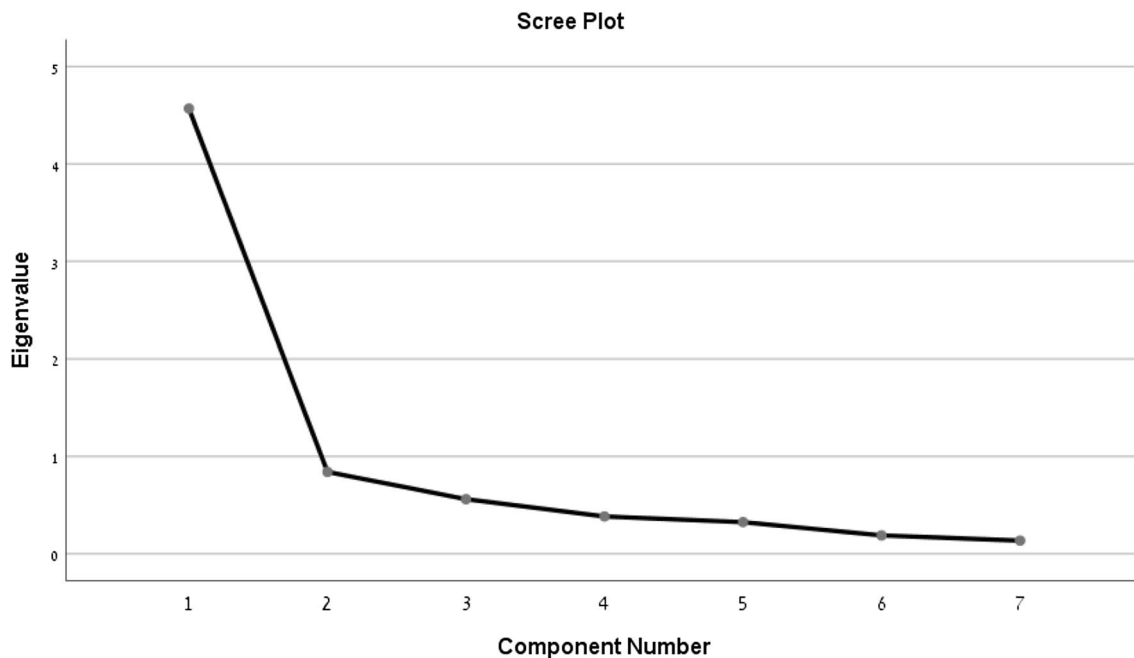


Fig. 2 Scree plot of rotated principle axis factor analysis (Varimax) for seven FAS, RRB accommodation items



## Discussion

This is the first study to examine family accommodation of core ASD symptoms. Accommodation of RRBs was highly prevalent, with 80% of parents engaging in family accommodation at least once a month and 55% reporting daily accommodation of their child's RRBs. These accommodation rates are similar, albeit slightly lower, than those reported in pediatric OCD (Lebowitz et al. 2016) and anxiety disorders (Lebowitz et al. 2013; Lebowitz et al. 2016; Lebowitz et al. 2014b; Thompson-Hollands et al. 2014), and of anxiety symptoms in children with ASD (Storch et al. 2015). The most common accommodations were providing symptom-related items, participating in symptom-related actions and assisting avoidance of symptom-related stimuli.

Importantly, and consistent with our hypothesis, higher levels of accommodation were strongly associated with higher RRB severity. Additionally, higher levels of accommodation were associated with poorer communication and daily living skills in the children, and a majority of parents reported feeling distress due to the accommodation. Most parents also reported their children responding aggressively to not being accommodated. These results also parallel previous findings in children with OCD and anxiety disorders (Lebowitz et al. 2013, 2016; Thompson-Hollands et al. 2014).

Results support the usefulness and sound psychometric properties of FAS-RRB, currently the only instrument available for assessing family accommodation of RRBs. Interestingly, results support a single factor to account for the accommodation items of the FAS-RRB, whereas factor analysis of accommodation items for anxiety disorders and OCD have indicated the presence of two factors, comprising active participation in symptom-driven behaviors and modifications to family routines and schedules (Albert et al. 2010; Lebowitz et al. 2013), or avoidance of OCD triggers and involvement in compulsions (Flessner et al. 2010; Lebowitz et al. 2013). This could be due to differences between anxiety and OCD symptoms and RRBs, and the kinds of accommodation they elicit.

The cross-sectional nature of the current data precludes drawing conclusions about the causal links tying family accommodation to severity of RRBs or adaptive functioning. It is plausible that higher RRB severity and lower adaptive functioning may lead to increased family accommodation, or that, as has been suggested in other disorders, family accommodation may lead to more severe child symptoms and to greater functional impairment. Indeed, the relationship may be bidirectional and cyclical, indicating a combination of the first and second possibilities. Longitudinal data is required to explore these hypotheses.

The factors that drive or maintain family accommodation in parents of children with ASD also require further

examination. When parents in the study were asked to qualitatively describe their child's RRBs, some used language indicating their belief that these behaviors were not optional, such as "must" or "have to" to describe both the RRBs and their own accommodations. As such, parents of children with ASD may be providing accommodations because of their belief that there is no other choice. Children's aggressive responses to not being accommodated, reported by a majority of parents, likely also contribute to maintaining the accommodations over time.

While results suggest similarities between family accommodation of RRBs in ASD and family accommodation of symptoms of OCD and anxiety disorders there are also important differences to consider. Every child with ASD presents with RRBs, but the frequency, severity and nature of these behaviors vary widely. Some children with ASD are predominantly challenged in the arena of social communication and interaction with only few or rare RRBs. As such, some parents may have few RRBs to accommodate, whereas in OCD and anxiety the symptoms that families accommodate (e.g., avoidance behaviors, reassurance seeking or compulsive rituals) are, at times, the major manifestation of the disorder. This may help to explain the somewhat lower rates of accommodation reported by the parents of children with ASD relative to what has been reported in OCD and anxiety disorders. Moreover, children with low levels of RRBs, whose parents thus have few symptoms to accommodate, may have contributed to the correlation between these variables. This may help to explain the strong correlation found in our study (.808), compared to the correlations between symptom severity and family accommodation found in work focused on childhood OCD and anxiety disorders (e.g. .35–.65; Lebowitz et al. 2013, 2014b; Storch et al. 2007, 2010).

Another distinction between RRBs and the symptoms of OCD and anxiety relates to their presumed function. While symptoms of OCD and anxiety disorders are intended to relieve anxiety or distress (APA 2013), different RRBs serve different functions, and even similar RRBs may serve diverse functions for different children (Leekam et al. 2011; Stratis and Lecavalier 2013). It is therefore important to remain modest regarding any generalizations concerning RRBs.

An important clinical question that arises from the study and that requires additional research is what guidance should be provided to parents about accommodating their children's RRBs. In both OCD and anxiety disorders current interventions emphasize the gradual and supportive reduction of family accommodation as a path to increasing independent coping in the child (Lebowitz 2016; Kagan et al. 2016; Lebowitz et al. 2018; Salloum et al. 2018). At least one parent-based intervention for OCD and anxiety disorders focuses on reduction of family accommodation as the central objective

of treatment, and has been found to improve child symptoms (Lebowitz 2013; Lebowitz and Omer 2013; Lebowitz et al. 2014a, b). It may be that a similar approach would be beneficial in cases of ASD. Development and testing of such an intervention could lead to additional, and direly needed, treatment tools for ASD.

Our results should be interpreted in light of several limitations. First, our sample was small and comprised a broad age range. To mitigate this concern we first analyzed data separately for two age groups (ages 0–6 and ages 6–15) and the analyses did not reveal significant differences between the ages. We thus present the results for the combined sample. Additionally, given the preliminary nature of the study, we did not correct our alpha, even though multiple analyses have been performed. Significantly, our results are based on an examination of families at the time of initial diagnosis. These results reflect the level of accommodation seen in families heretofore unfamiliar with the nuances of ASD and it is possible that understanding of the symptomatology will inform the way in which parents react to RRBs. Additionally, the questionnaires were completed by a single parent of each child, thus presenting a partial description of the response of the child's family to their symptoms. Finally, while the body of literature on family accommodation of OCD and anxiety disorders includes longitudinal and intervention studies (Lebowitz et al. 2016), we collected data at a single time point, thus precluding any understanding of the nature of the correlational relationship or the longitudinal effects of family accommodation.

Future research should address these limitations and contribute further to our understanding of family accommodation of RRBs. Longitudinal studies, evaluating the relationship between family accommodation of RRBs and symptom severity at different time points and developmental stages, may inform our understanding of the mechanisms behind the indicated associations. Future studies including larger samples may also indicate the possible effects of factors such as age, gender, and cognitive skills on family accommodation and its consequences. An examination of qualitative data regarding family accommodation of RRBs may provide further insight into the processes that drive it and the impact it has on families.

Despite these limitations, this preliminary investigation of family accommodation of RRBs in ASD provides novel and valuable information. Accommodation is prevalent among parents of children with ASD; relates to symptom severity; and causes distress for many parents. Deeper understanding of this new area could lead to novel insights into phenotypic heterogeneity and may inform the development of novel interventions.

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**Author Contributions** JK and ERL conceived of the study, and participated in its design and coordination along with IF and DAZ; JK, ERL and CS participated in measurement design; IF was responsible for data collection and organization along with EBI; DAZ was responsible for all clinical characterization; IF performed the statistical analyses; IF and JK were responsible for interpretation of the data; IF drafted the manuscript with JK; All authors read and approved the final manuscript.

## Compliance with Ethical Standards

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the medical center's research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

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