

EXPLORING HOW FAMILY ACCOMMODATION INFLUENCES REPETITIVE BEHAVIOURS IN CHILDREN WITH AUTISM: A MIXED-METHODS STUDY

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ABSTRACT

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Diagnosis of Autism Spectrum Disorder (ASD) is significantly influenced by restricted and repetitive behaviors and interests (RRBI). These behaviors frequently pose the most substantial obstacles in the daily lives of children with ASD and their families. Nevertheless, there is a scarcity of research that examines family accommodation behaviors (FAB) within the ASD community, and the relationship between these accommodations and the specific features of the children's behaviours is as yet undecided. Utilizing a sequential mixed-methods approach, the objective of this study was to explore the connection between RRBI and FAB in order to acquire a better understanding of the lived experiences of parents with their children's RRBI. The investigation was implemented in two phases: a quantitative phase and a qualitative phase. Initially, 29 parents of autistic children aged 5–13 accomplished questionnaires. Subsequently, 15 of these parents were interviewed concerning their children's RRBI and FAB. In the qualitative phase, extensive phenomenological interviews were conducted. It was discovered that there is a robust positive association between RRBI and FAB, as well as between their sub-components. These findings were further substantiated by the qualitative data, which provided illustrative examples of the compromises that families make in order to address RRBI-related issues. Overall, the investigation underscores the significance of addressing both autism-related behaviors and the experiences of parents, as each influence and is influenced by the other, thereby emphasizing the interconnectedness of RRBI and FAB.

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INTRODUCTION

The fundamental tenet of home-centered therapy is that the family unit as a whole is responsible for the child's optimal development. Respect for families, information sharing for informed decision-making, and equal cooperation and collaboration taking family choices into account are the hallmarks of this model (American

Academy of Pediatrics, 2012; Gafni-Lachter, 2015). Disabilities in social communication and conduct are hallmarks of ASD, a neurodevelopmental illness that persists throughout a person's life (American Psychiatric Association, 2013). The prevalence of ASD in Pakistan is estimated to be 1 in 36 children in 2023, according to the CDC. RRBI and difficulties with social communication and engagement are clinical hallmarks of ASD (American Psychiatric Association, 2013). Similar to individuals with other developmental impairments and those with typically developing brains, individuals with RRBI exhibit behaviors like obsessions, rigidity, resistance to change, and repetition (Bury et al., 2021; Yaari & Dissanayake, 2021). On the other hand, RRBI is more prevalent and variable in ASD youngsters (Harrop et al., 2014).

Low-order RRBIs include sensory-seeking activities and repeated bodily motions, while high-order RRBIs involve ritualistic behaviors and restricted interests. According to Bishop (2015) and Turner (1999), RRBIs are typically more common among younger children with developmental delays and lower cognitive abilities, whereas higher-order RRBIs are more frequently observed in children with greater cognitive and language proficiency. These classifications generally reflect the child's functional level. These behaviors influence various aspects of daily life, including routines, social interactions, and self-care. For instance, an autistic child may consistently refuse to change out of their uniform, irrespective of the weather conditions (Goldfarb et al., 2021; Yaari & Dissanayake, 2021). Problematic conduct like this might make it challenging for the child and their family to adhere to schedules or participate in daily activities (Lewis & Bodfish, 1998; Lam & Aman, 2007). Social exclusion and stigma can result from these behaviors (Johnco et al., 2021), which in turn might hinder social engagement and the formation of adaptive regulating techniques (O'Nions et al., 2018).

Causes of RRBI have not been fully determined; however, studies suggest that structural brain abnormalities could play a role (Casillas et al., 2021) and that these behaviors can manifest inversely reliant on variables such as gender, age, and cognitive ability (Holland, 2020). Researches and conversations with autistic individuals display those repetitive behaviors aid in managing stress and sensory overload, despite societal negative perceptions of these habits (Shimshoni et al., 2022). David (2021) and Lucyshyn et al. (2004) found that narrowing one's interests might sometimes enhance communication skills, deepen understanding of specific topics, and even open doors to new professional opportunities.

To comprehend the impact of RRBI on the daily lives of autistic children, therapists must understand its role. FAB are developed in response to family challenges and help children cope with adversity (Caporino et al., 2012). Two definitions of FAB appear in the literature; both relate to functional family responses to the difficulties of caring for a child with developmental disabilities (Benito et al., 2015). One perspective view FAB as a set of positive strategies that can enhance family well-being (Flessner et al., 2011). Services for families, housing, child care, and emotional and physical well-being have had to adapt (Johnco et al., 2021). According to Caporino et al. (2012), another perspective on FAB is that it involves actions taken to prevent children from becoming distressed or having tantrums. These actions could include altering family plans or providing comfort. Despite their protective intentions, these actions may impede children's ability to learn adaptive coping mechanisms (Johnco et al., 2021).

For therapists assisting families with autistic children, these divergent perspectives on FAB present challenges. While the first view suggests that FAB can improve the child's functioning and support therapeutic efforts,

the second view holds that FAB might limit the child's interaction with their environment. The difficulties faced by families parenting an autistic child, especially one with comorbidities, are substantial (Russell et al., 2013). Increasingly, studies are examining FAB in relation to ASD, with evidence indicating that most parents of autistic children who also experience anxiety problems use FAB regularly (Storch et al., 2021). According to Johnco et al. (2021), these actions are associated with more severe symptoms and functional limitations. Parents often modify their daily routines, reduce their child's exposure to stressful situations, and avoid unexpected events to manage challenging behaviors (Caporino et al., 2012). Identifying and addressing these behaviors is crucial for therapists, as they significantly impact the child and treatment strategies.

The purpose of this research is to address a significant knowledge gap regarding how FAB influences RRBI in autistic children. According to Caporino et al. (2012) and Johnco et al. (2021), RRBI play a crucial role in ASD and greatly affect the child's and families' daily lives. Few studies have examined the interaction between FAB and RRBI, despite the common occurrence of FAB (Bishop, 2015; Turner, 1999). We employed a mixed-methods approach, combining quantitative tests with qualitative interviews, to explore this interaction. Using established measures such as the RBS-R and the FAS-RRB, the quantitative phase examined the correlation between RRBI and FAB (Bury et al., 2021; Yaari & Dissanayake, 2021). The relationship between the two was supported by statistical correlations, but families' experiences and coping mechanisms were better understood through in-depth qualitative interviews (Casillas et al., 2021; Holland, 2020). Clinical interventions and family-centered care for individuals with ASD can be informed by the combined insights provided by both approaches, offering a holistic perspective on the interplay between RRBI and FAB (Howard et al., 2019; O'Nions et al., 2018). Clarifying these connections can lead to more targeted treatments for families with autistic children. The qualitative component of the research explores key issues regarding parents' perspectives on their child's daily activities and the adjustments they make to meet their needs.

METHODS AND PARTICIPANTS

The study utilized a sequential mixed-methods explanatory design (Gergen & Gergen, 2012; Teddlie & Tashakkori, 2012), comprising two phases of data collection: quantitative and qualitative. This methodology facilitated gathering quantitative data on the frequency and features of restricted and repetitive behaviors (RRBI) and functional adaptive behaviors (FAB), followed by qualitative interviews that augmented the validity and comprehensiveness of the findings (Polit & Beck, 2017).

PROCEDURE

Quantitative Phase: The quantitative data involved parents of 29 autistic children, selected through non-probability convenience sampling. Inclusion criteria required (a) parents of children aged 5-13 and (b) an official medical diagnosis of ASD, confirmed by the Autism Diagnostic Observation Schedule (Lord et al., 2000). Exclusion criteria ruled out parents of kids with known genetic disorders associated with autistic indications, metabolic diseases, or significant mental health issues (e.g., psychosis, drug addiction).

Qualitative Phase: Participants from the quantitative phase were invited to participate in the qualitative stage, where 15 parents consented to interviews, concluding upon reaching data saturation (Guest et al., 2006). Deliberate sampling followed similar criteria as the quantitative phase, with additional requirements for active

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caregiver participation and language proficiency for conducting in-depth interviews. A phenomenological approach was used to explore parents' experiences and perspectives on their child's RRBI and FAB, with interviews lasting 35 to 60 minutes, recorded via secure Zoom software.

MEASURES

- **Repetitive Behavior Scale-Revised (RBS-R)**: This 43-item scale measures the frequency and severity of repetitive behaviors over the past month. Items are rated on a 4-point Likert scale and are divided into six subscales. The RBS-R demonstrated strong internal reliability in this study (Cronbach's $\alpha = 0.930$).
- **Family Accommodation Scale for Restricted and Repetitive Behaviors (FAS-RRB)**: This scale evaluates FAB related to RRBI in autistic children. It showed high internal consistency in this study (Cronbach's $\alpha = 0.810$).

The study aims to contribute to a deeper understanding of how FAB influences the expression of RRBI, which could have significant implications for treatment strategies and family-centered care in the context of autism.

DATA COLLECTION

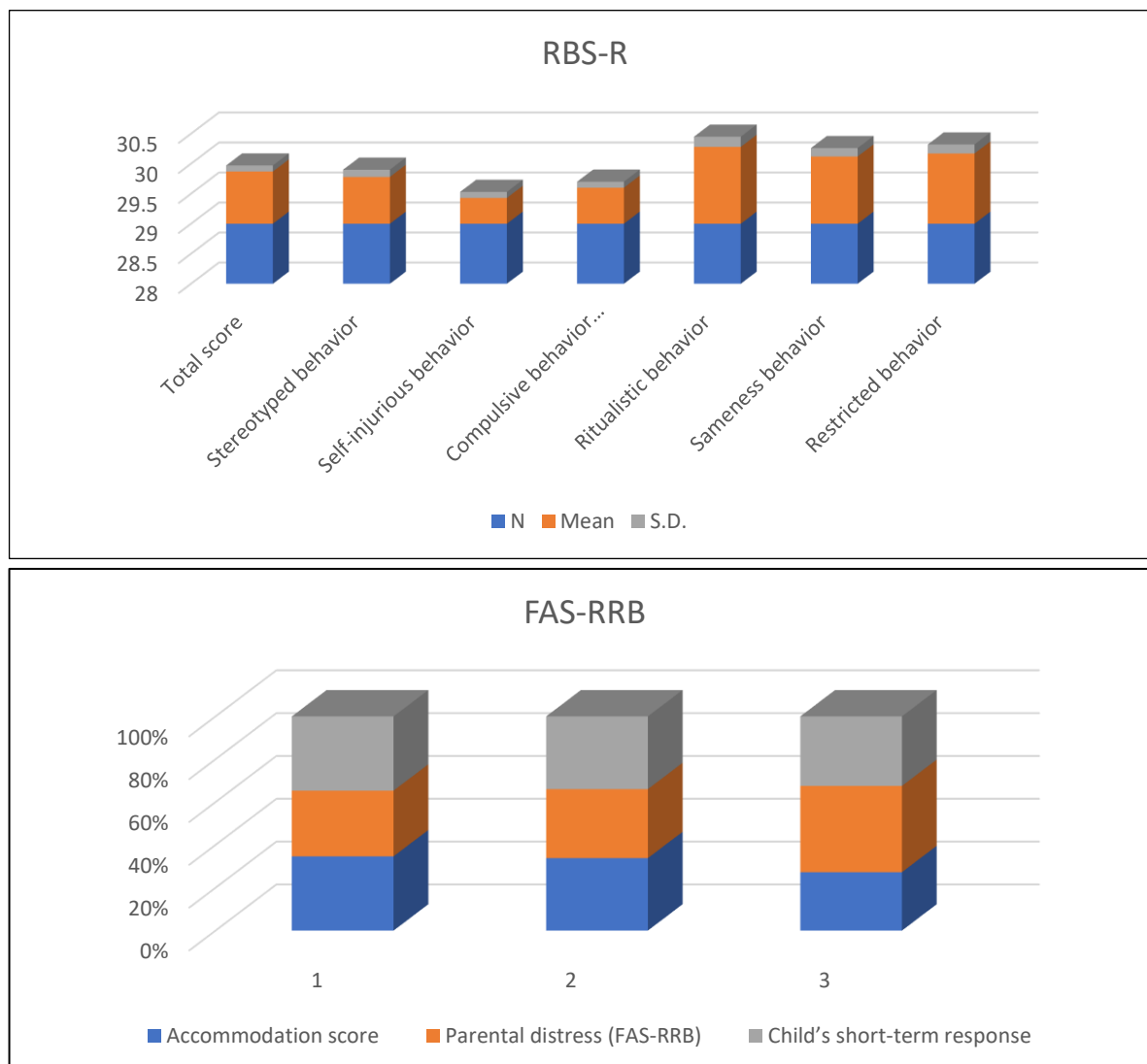
- **Interviews**: Semi-structured interviews, designed with primarily open-ended questions, focused on exploring RRBI behaviors, their functional impact on the child's life, and the ways in which families accommodated these behaviors. Conducted by a PhD student and an experienced occupational therapist via secure Zoom sessions, each interview lasted between 35 to 60 minutes. This method allowed for rich, detailed responses from participants, offering qualitative insights into how RRBI affected both the child and the family unit.
- **Data Analysis**: Quantitative data was analyzed using SPSS (version 27). Descriptive statistics were applied to examine demographic variables, and due to the small sample size and non-normal distribution of the variables, Spearman correlation tests were used to investigate the relationship between RRBI and FAB scores. For the qualitative data, a systematic phenomenological approach was employed. This involved coding the data, constructing categories, and identifying key themes. To ensure the reliability of the findings and reduce bias, three independent researchers coded the data, supported by in-depth quotes and thorough process documentation.

RESULTS

Quantitative Findings: The study included mostly mothers (28 married, 1 single) from Jewish backgrounds, with varying degrees of religious affiliation: 52% identified as non-religious, 24% as traditional, and 17% as ultra-Orthodox. The children in the study (mean age = 7.7 years, $SD = 0.41$) were predominantly male ($n = 24$), consistent with the higher prevalence of autism in boys. Most of the children exhibited severe ASD symptoms (77%), with 19% displaying moderate symptoms and 4% showing mild severity. The descriptive analysis revealed that ritualistic behaviors were the most common form of RRBI ($M = 1.29$, $SD = 0.17$), while self-injurious behavior was the least common ($M = 0.44$, $SD = 1$) (Bodfish et al., 1999).

This mixed-methods approach provided a comprehensive understanding of how RRBI behaviors manifest in autistic children and how families adapt to these challenges through accommodations. The integration of both

quantitative and qualitative findings offers valuable insights into the complex dynamics of family life for children with autism, paving the way for more targeted interventions and support.



DESCRIPTIVE STATISTICS: QUESTIONNAIRES FOR RBS-R AND FAS-RRB

The (RBS-R) & (FAS-RRB) scales were utilized to collect data in this study. These instruments assess the repetitive behaviors of children with autism and the manner in which families accommodate these behaviors. The mean (M) of the total score for repetitive behaviors across the 29 children was 0.87, with a standard deviation (SD) of 0.10. Breaking down specific behavior categories, stereotyped behaviors had a mean of 0.78 (SD = 0.12), while self-injurious behaviors had a mean of 0.43 (SD = 0.10). Compulsive behaviors had a mean of 0.60 (SD = 0.10), and ritualistic behaviors were the most pronounced, with a mean of 1.28 (SD = 0.17). Sameness behaviors and restricted behaviors had means of 1.12 (SD = 0.14) and 1.17 (SD = 0.15), respectively. These results indicate a strong inclination towards repetitive and restricted behavior patterns in the children.

The accommodation score for the 26 families had a mean of 2.10 (SD = 0.21) on the FAS-RRB, which assesses family accommodation strategies. The mean score of 2.00 (SD = 0.31) reported by 23 families indicated that parental distress associated with accommodating their child's needs was somewhat lower. Among the 26 children, the short-term responses to these accommodations had a mean of 2.11 (SD = 0.25), suggesting a significant but varied response to the accommodations implemented by their families.

year-old, described her son's repetitive behaviors as a source of relaxation and enjoyment derived from auditory stimulation: "He finds pleasure in opening and closing doors, especially the sound of slamming. He repeats this behavior incessantly." Many participants also noted that their children faced difficulties with daily activities due to a reliance on rituals and consistency. M, the parent of a 9-year-old, described a specific morning routine: "He refuses to drink chocolate milk while wearing socks... or in other similar situations." Some participants reported problematic behaviors related to intense interests in specific subjects. For example, N described her 11-year-old's obsession with collecting CDs: "He has an intense interest in CDs. We have several hundred CDs at home, and whenever we pass a store with CDs, he grabs one and runs away." Such extreme interests can sometimes lead to dangerous situations, highlighting the challenges these behaviors pose for both children and their families.

PARENT AND FAMILY CHALLENGES

All parents in the study faced challenges managing their children's non-adaptive RRBIs. Interviews revealed feelings of blame, married and family stress, and a continuous need for self-directive due to the demands of raising a child with autism. Many negative emotions were tied to the constant requirement to engage in functional adaptive behaviors (FAB) throughout the day. For example, M, the mother of a 9-year-old, described the exhaustion of addressing her child's needs at bedtime: "We had to sit next to him for hours. It was unbearable. One of us would stay there until 11:30 p.m., staring at the ceiling, feeling desperate. We often say it's a marvel we didn't get divorced." Family events involving extended relatives also required meticulous preparation. S noted that she had to prepare her 9-year-old in advance to avoid inappropriate behavior during social gatherings: "There was always anxiety about what he might do. We would literally instruct him before every event: 'You can't touch anybody; you can't sit on anyone.' It formed a lot of pressure, yes. Continuous changes, constant reminders—it was awful. It's distressing to spend the whole day telling your child what not to do."

The effort required to accommodate a child with autism often led to increased conflict, arguments, and tension within the household. N elaborated on the strain it placed on her family: "I had to accompany him everywhere, even to the bathroom. We had a refrigerator on the balcony, but I couldn't let him go out there alone. This caused a lot of strain in the house because I couldn't continuously go with him, so I'd ask his sisters to help, and they'd become frustrated. It became a source of significant complexity for the family."

“YOU JUST CAN’T PLACE THE CHILD’S TRACK FOR HIM ALL DAY”

The behaviors exhibited by the children had a profound impact on their entire families. Parents continually sought ways to balance their child's needs with those of other family members. The FAB discussed in the interviews revealed that parents had to make daily adjustments to meet their children's specific needs. L explained how she had to modify her 7-year-old's clothing to prevent him from engaging in inappropriate behaviors: "He's always engaging in this particular behavior. We had to sew his shirt to his pants and put a zipper on the back to prevent it." Another parent, R, recounted the challenges of establishing a "surprise-free routine" for her 5-year-old: "Any small change can upset him. Whether it's the phone not working, not being able to download a game, or the neighbor turning on the elevator light before him... it could be something

trivial like an elevator light or a computer malfunction. If I promise something and it doesn't happen, he gets very upset." G, the mother of a 12-year-old daughter, described her daughter's difficulty with change and the need for meticulous preparation: "She needs to be prepared in advance for everything. You can't just say, 'Let's go now,' because it won't work. You have to tell her exactly what will happen and follow a schedule. She doesn't cope well with changes."

A significant majority of parents (66.6%) reported difficulties with family outings, often facing the choice of either bringing their child with autism or abandoning plans altogether. P, the mother of an 8-year-old, described how they had to adapt family outings to accommodate their child: "We've had to adapt. If a place isn't suitable for him, then we don't go. For example, we avoid crowded places or areas with too much noise. When we do take him, one parent stays with him while the other monitors him. It changes our lives significantly." P also noted how her family adjusted vacations to suit her son's behaviors: "If he's making noise, spinning around, or yelling—it becomes a disturbance. So when we go on family vacations, instead of staying in a hotel, we rent a guest cabin to stay isolated from other families." These accounts highlight the extensive impact of a child's RRBI on family routines and involvement in social and community events. Parents frequently used self-regulation strategies, such as patience and empathy, to manage their child's challenging behaviors. P reflected on maintaining composure when dealing with her 10-year-old's behaviors: "Today, my son didn't want to brush the teeth because of a movable tooth. I've asked him dozens of times, and I'm exhausted. Eventually, I lose my patience, and it becomes unpleasant. My strategy is always to calm myself down, to be the calm figure in the house."

Several parents emphasized the importance of professional support in managing their children's behaviors. P shared how a therapist provided essential tools that made a significant difference: "We happened to meet a therapist, and he gave us new tools and perspectives on how to respond. The lockdown during the pandemic gave my husband the opportunity to implement focused intervention strategies, and it made a remarkable difference. After the lockdown, our child returned to school as a different person. The school had been pressuring us to see a psychiatrist, but thanks to this new approach, we didn't need to."

DISCUSSION OF FINDINGS

This study explored the relationship between restricted and repetitive behaviors (RRBIs) and functional adaptive behaviors (FAB) in families with children on the autism spectrum. Findings highlight the substantial effect of RRBIs on both the children's functioning and their families' everyday lives. All parents described using FAB at least once a month, with 76% employing these strategies daily. These results are consistent with Feldman et al. (2017), who found 80% of parents reported monthly FAB use, and 55% used them daily. The interviews revealed a variety of FAB utilized by parents at home, with a strong positive correlation identified between RRBIs (measured by the RBS-R) and FAB (measured by the FAS-RRB). Specifically, higher-order RRBIs, such as compulsions, ritualistic behaviors, sameness, and restricted behaviors, were significantly associated with FAB. These behaviors are commonly seen in children with advanced cognitive and verbal abilities (Levy et al., 2010; Rutter et al., 2003).

The environment often necessitates that these children engage in more adaptive behaviors, leading parents to invest significantly in FAB to support their child's functioning both at home and in the community. During

interviews, parents detailed their efforts to establish consistent routines or modify clothing to address compulsive behaviors (Gillberg, 1998). Notably, no significant correlation was found between lower-order RRBIs and FAB, despite the presence of these behaviors in the children studied. This suggests that parents are more inclined to accommodate higher-order RRBIs than lower-order ones. Previous research indicates that the degree of deficiency and ecological demands may influence FAB (Volkmar & Cohen, 1991).

Parents' insights of their children's performances likely influence their decisions to implement FAB. Research suggests that RRBIs help regulate children's stress and anxiety (Ozonoff et al., 2008; Lord & Rutter, 2012). Consequently, parents may view lower-order RRBIs as functional, especially when these behaviors have a calming effect. In interviews, some parents construed their children's repetitive behaviors as self-calming (e.g., repeatedly opening and closing doors) (Happé et al., 2006). Modifying these behaviors is often challenging and may lead to avoidance by parents (Matson & Nebel-Schwalm, 2007).

Additional research indicates that parents invest considerable effort in FAB (Bishop et al., 2004; White et al., 2009). The quantitative and qualitative data from this study support these findings, with parents reporting environmental adjustments and efforts to minimize stressors to prevent frustration for both the child and the family (e.g., choosing isolated cabins over crowded hotels for vacations) (Scahill et al., 2015). Participants also noted that FAB reduced the likelihood of challenging behaviors, consistent with existing research (Wong & Kamps, 2015). However, excessive family accommodation may inadvertently perpetuate anxiety and compulsive behaviors in children (Feldman et al., 2017; Wood et al., 2018).

Finally, the majority of participants (83%) emphasized the importance of professional guidance in addressing their child's RRBIs. Research highlights the crucial role of professionals in helping parents develop and implement effective FAB (Kazdin et al., 2013; Kane et al., 2019). A combination of psychological support and new behavioral tools proved particularly beneficial for managing the challenges associated with their child's RRBIs (Mandell et al., 2010). FAB typically focuses on controlling the environment, while professional guidance provides strategies for fostering adaptive behaviors and integrating children with autism into everyday life. Thus, professional support is indispensable.

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