Published in final edited form as:
Autism. 2019 July ; 23(5): 1236–1248. doi:10.1177/1362361318810217.

Parent and professional perspectives on behavioral inflexibility in autism spectrum disorders: A qualitative study

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Abstract

Restricted and repetitive behaviors (RRBs) are a core feature of autism spectrum disorder (ASD), however, research on the functional impact of these behaviors on the quality of life for individuals with ASD and their families remains scarce. We conducted focus groups with parents of children with ASD and clinicians in order to better characterize the functional impact of behavioral inflexibility (BI), which represents one potential dimensional construct that could account for the breadth of behaviors comprising the RRB domain. Transcripts of the focus groups were analyzed using qualitative analysis coding methods to determine parent and clinician beliefs on a range of issues related to BI including overall impact, types of child behaviors, and strategies for managing BI. Thematic analysis revealed that parents and clinicians view BI as an important behavior that impacts multiple areas of functioning, relates to other RRBs as well as social communication behaviors, and warrants targeted treatment. Notably, many parents and clinicians emphasized some positive consequences of BI as well. These findings add crucial insights into the functional impact of BI and RRBs as a whole, and suggest that BI represents an important avenue for future research.

Introduction

Restricted, repetitive behaviors (RRB) are a core feature of autism spectrum disorder (ASD). A number of behaviors comprise RRBs, including stereotypies, repetitive self-injury, insistence on sameness / routines, compulsions and restricted interests (Bodfish, Symons, Parker, & Lewis, 2000; Lam & Aman, 2007). Within the context of ASD, these behaviors have been conceptualized to lie on a continuum ranging from “lower order”, motoric behaviors (e.g., stereotypies) to “higher order”, cognitive behaviors and processes (e.g., restricted interests, need for sameness) and empirical studies support this continuum (Bishop et al., 2013; Richler, Bishop, Kleinke, & Lord, 2007). There still remains a question as to what potentially underlies and connects this broad class of behaviors and how these behaviors associate with social communication symptoms. Behavioral inflexibility (BI) is one potential dimensional construct that has garnered increased attention, and that could account for the breadth of behaviors and functional impairments under the RRB domain as well as behaviors under the umbrella of social communication. However, little is known about the functional impact of BI for individuals with ASD and their families.

First person accounts of RRBs in persons with ASD have added another important source of information to our evolving understanding of the impact of these behaviors. These accounts often support the adaptive strength or resiliency interpretations of RRBs (Maloret & Scott, 2017; Smerbeck, 2017; Cho et al., 2017) and clearly indicate that in at least a subset of persons with ASD, RRBs are not perceived to be associated with any type of functional impact, would not be targeted for treatment, and in fact may be seen as a positive feature of ASD. However, missing from this approach to understanding RRBs are developmentally younger persons or persons with the most severe manifestations of ASD. In these cases, expressive language deficits or other features can preclude the possibility of using self-report or personal narratives as a means for determining the impact of RRBs. This paired with the established heterogeneity of ASD expression across individuals indicates that over-reliance on a personal narrative based model of RRBs risks missing the subset of cases where RRBs may indeed be associated with some degree of functional impairment.

In order to elicit stakeholder input on the potential functional impact of RRBs as opposed to the phenomenology of RRBs more generally, we chose in this study to focus on BI, one specific aspect of RRBs. BI is a complex construct that encompasses aspects of cognition (e.g., executive function) and behavior (i.e., overt acts of inflexibility) (D’Cruz et al., 2013; Strang et al., 2017; Uddin et al., 2014), with both impacted by environmental situations that elicit and reinforce inflexible responding. Herein, BI is meant to refer to rigid and inflexible patterns of behavior that contrast with the need to be flexible, open to change, and amenable to the inevitable need to change and adapt in the context of the complex and often unpredictable demands of one’s surroundings.

Although researchers have begun to examine BI in ASD, they have primarily focused on aspects of neurocognition, such as reversal learning (D’Cruz, Mosconi, Ragozzino, Cook, & Sweeney, 2016) or cognitive flexibility/inflexibility (Poljac, Hoofs, Princen, & Poljac, 2017; Strang et al., 2017); thus, there is still a need to understand the behavioral and environmental contributors to, and implications of, inflexibility. On the behavioral side, studies have somewhat narrowly focused on reinforcement contingencies that maintain inflexible behavior. For example, both basic science and clinical translational studies have examined variability in behavioral responding (Holman, Goetz, & Baer, 1977; Neuringer, Deiss, & Olson, 2000; Miller & Neuringer, 2000), or in essence, how to make reinforcement contingent on the display of more variable behavior. Yet, many of these studies were conducted in clinical settings. To best understand the intersection of behavior and environment, it is essential to gather the perspectives of those who interact with individuals with ASD on a daily basis. Even when studies have attempted to measure (or gather) parent perspectives, they have often restricted their sample to children with ASD with intact cognitive abilities (e.g., Strang et al., 2017). There is still a need to understand how issues of BI manifest and impact daily life for the full spectrum of those with ASD in order to develop externally valid outcome measures and treatments.

Understanding personal perspectives on child health and behavior generates useful and useable information, on both the nature of the child's condition and how it affects family functioning (Murphy, Christian, Caplin, & Young, 2007). When Murphy and colleagues (2007) conducted focus groups with parents who had children with chronic conditions, the parents raised such issues as increased levels of stress and worry about the future, and that the child's health status had negatively impacted their own physical and mental health. Thus, it is important to consider the family unit and how the child's disability or condition occurs within the context of a larger environment (e.g., home and school). This further necessitates the need to obtain the insights and perspectives of those who operate within these contexts in order to fully capture impact on daily life. Relatedly, parents of children with ASD are amongst the most stressed of those with children with disabilities (Boyd, 2002; Hayes & Watson, 2013), so gathering their perspectives on difficult behavior, such as inflexibility, may inform our understanding of parent coping and resilience to counteract the negative effects of stress. It is to be expected that some parents and professionals are finding ways to manage these challenges.

The purpose of this study was to obtain a corpus of parent and clinician input on the functional impacts associated with BI in children with ASD. Qualitative research provides one method to understand constructs by systematically gathering and analyzing the personal narratives (Corbin & Strauss, 2014) of parents and professionals who live and work with individuals with ASD parents and those who work clinically with individuals with ASD are necessary and acceptable surrogates to understand how BI manifests and the impact it has on the family and daily activities. The resulting product of our qualitative data collection and analysis was a set of common themes and subthemes that could be reliably identified by multiple raters and that were articulated by both parents and clinicians.

The specific research questions addressed through the focus groups were: (1) What are parents' and professionals' perspectives on BI in children with ASD (ages 2 – 17); (2) How does BI manifest in everyday life?; and (3) How does BI impact daily life for the child and the family?

Methods

Overview.

We used focus groups to understand the perspectives of parents and professionals on BI in ASD. Focus groups provide researchers an in-depth way to inductively gather information regarding key issues, ideas, and concerns from multiple participants at once (Hesse-Biber & Leavy, 2011). Focus groups specifically conducted with parents or other caregivers of children with ASD have shed light on a range of issues, such as family stressors and coping strategies (Resch et al., 2010), perceptions on therapeutic approaches (Allgood, 2005), and the development of outcome measures (Bearss et al., 2016; Hollin, Young, Hanson, Bridges, & Peay, 2016; Perfetto, Burke, Oehrlein, & Epstein, 2015; Anatol et al., 2013). Thus, this methodology represents a feasible and viable option to understand the everyday impact of BI for caregivers of children with ASD and clinicians who work with this population.

Focus group data were collected at three clinical sites in the United States over a 3-month period (September – November 2015). The study was approved by the Institutional Review Boards at all sites prior to data collection. The team consisted of three site PIs who served as content experts and moderated all focus groups. Additionally, two qualitative methods experts, three research assistants and one post-doctoral fellow assisted with coding, data management and analysis of all qualitative data.

Participants.

Focus group participants included both caregivers of children and adolescents with ASD and clinicians who worked with children with ASD in this same age range.

Caregivers.—Across the caregiver focus groups, we used purposive sampling to ensure the inclusion of caregivers of children and adolescents with ASD across our full age range of interest (2 – 17 years; i.e., the potential age range for the BI outcome measure). One focus group recruited only caregivers of girls with ASD to ensure we captured aspects of BI that may be unique to females on the spectrum. Caregivers were recruited from existing participant data banks at the clinical sites. Inclusion in data banks required a clinical diagnosis of ASD and caregivers completed a brief screener prior to participation to confirm their child's clinical diagnosis of ASD. Thus, at the start of the focus groups, caregivers completed the Social Communication Questionnaire - Current (SCQ; Rutter, Bailey, & Lord, 2003) – a brief caregiver report measure that evaluates communication and social abilities in children.

Thirty caregivers participated in one of four focus groups (mean group size = 7; range = 6 – 9; Table 1). The majority of the caregivers were female (n = 27) and non-Hispanic white (n = 20). The age of participants ranged from 24 to 58 years (mean = 40.2; SD = 8.34). The age of the children of participants (17 boys; 13 girls) ranged from 2.5 to 17 years (mean = 99 months; SD = 60.78). Children of the participants were currently in a range of educational placements (Table 1). The mean SCQ score for the children was 16 (SD = 8). However, there was a lot of variability in scores. 18% of children fell below the cut off of 11 (non-ASD developmental delay specific cut off; Marvin et al., 2017). This included three females. 28% fell between the cut offs for non-ASD and ASD. This was somewhat expected given the lower performance of the SCQ-Current for older children and those without co-occurring intellectual disabilities (e.g. focusing on imitation and pretend play; Barnard-Brak et al., 2016; Corsello et al., 2007; Eaves et al., 2006; Marvin et al., 2017). We still included the parents of these children because all children had received a prior clinical diagnosis of ASD and were still included in the participant data banks at their respective clinical site.

Clinicians.—Across the clinician focus groups, we also purposefully sampled clinicians who worked with children with ASD in our age range. Clinicians were recruited through existing provider networks at each of the three sites and through known contacts.

Twenty-five clinicians participated across the three focus groups (mean group size = 8.; range = 5–11; Table 2). General clinical experience ranged from 18 months to 45 years (mean = 16.83; SD = 12.72); whereas, specific experience working with individuals with ASD ranged from 6 months to 25 years (mean = 13.27; SD = 6.83). Clinicians were from a variety of professional backgrounds (Table 2) with the largest proportion of clinicians being licensed speech and language therapists. The majority of clinicians had master's level and above training/qualifications.

Procedures.

We conducted 7 focus groups across 3 sites to understand caregivers' (4 groups) and clinicians' (3 groups) perspectives regarding the BI of children with ASD. In qualitative research methods, there is no firm sample size or number of sampling opportunities needed to achieve results; rather, the goal is to achieve data saturation. Saturation is a concept in qualitative research that encapsulates the process of continued data collection until no new information is revealed, and a thorough understanding of all themes and sub-themes is achieved. Millward (2012) suggests that 4–6 focus groups with 6–10 participants in each group are needed to achieve data saturation. After conducting 7 focus groups, we found that we had obtained data saturation as well as a thorough description of our themes and sub-themes upon analysis of our focus group transcripts.

Development of focus group guide.—A focus group guide was developed as a way to maintain consistency, in particular when moderators may differ across groups, as well as provide appropriate prompts to focus group participants for rich data collection (Morgan, 1997). In order to generate semi-structured interview questions, the team utilized input from expert panels as well as existing literature on the topic of BI. A draft focus group guide was used to conduct two pilot focus groups (one each with caregivers and clinicians) in order to refine the interview questions. These guides were designed to elicit discussions on examples and triggers of BI in daily life, adjustments/strategies used by caregivers and clinicians to manage BI, and the overall impact (negative or positive) of BI on child and family activities. Example questions from the focus group guide are provided in Table 3. All focus groups were moderated by site PIs, in their capacity as content experts, and at least two other research staff were present at all focus group sessions for note-taking, consenting participants, and/or supporting logistical needs.

Training procedures.—To maintain consistency across sites, the first author developed an online moderator training describing the purpose of the focus groups and the specific procedures to be followed. All members of the research team reviewed the training materials and a follow-up conference call was conducted to address any specific concerns. Some key attributes of the training related to moderator behaviors during the focus group, including keeping personal opinions to self, demonstrating neutral affect and body language to prevent biased responses, trying not to interrupt participant thought processes, and using language from the focus group guide or participants' own words for follow-up questions or prompts, etc. These procedures would ensure a comfortable and non-judgmental environment during the focus group so that participants felt comfortable sharing their opinions and ideas.

Additionally, training procedures for coders were developed prior to data analysis. Coders reviewed a coding example and participated in several practice coding sessions in accordance with our data analysis strategies (described below). Frequent teleconferences were held for ongoing coding support and consensus coding was done throughout the data analysis process.

Data collection.—At the beginning of the focus group, participants were informed that all attempts will be made to ensure confidentiality and none of the participants would be identified in any reporting of the results. Once consent was granted by all participants, all focus group sessions were audio recorded. Ground rules for the focus groups also were established, such as members respecting each other's confidentiality and not sharing any information heard during the focus group with others.

During the focus groups, the moderators referred to the focus group guide for questions to be asked and associated prompts. After each question, the conversation was allowed to continue as long as new ideas were emerging that were relevant to the topic of BI. Follow-up questions were asked, as appropriate, and each member of the focus group was encouraged to share their opinions. In addition to audio recording the focus group discussions, a member of the research team was present at each focus group in the capacity of note-taker. Notes taken during focus groups are a means to provide context to the audio recorded transcripts. The specific notes were related to any memorable or well-said quotes, significant non-verbal behaviors, and areas of strong disagreements. Although notes from the focus groups were not coded or analyzed, the note-taker at each site was responsible for coding the audio transcript; thus, their notes provided rich context for the transcript coding and analysis process.

Data coding and analysis.—Verbatim transcripts were iteratively coded in detail by multiple raters across sites and analyzed using established qualitative coding analytic methods. Transcription was performed by a professional transcription service and transcripts ranged from 24 to 54 pages in length.

Thematic analysis (Braun & Clarke, 2006) was applied to identify emergent themes across the transcripts. First, a priori code concepts were created based on anticipated categories of responses to the questions on the focus group guide. These included *impact*, *child behavior*, *manifestation*, *strategies*, and *measurement*. In the first round of coding, four independent coders across the three sites completed line by line semantic coding (Boyatzis, 1998) of one transcript to generate approximately 650 initial codes under the a priori code concepts (see Table 4 for examples of code concept and select semantic codes). After checking for and removing codes because of duplication and overlap, the first author (master coder) created the *master codebook* comprised of 155 codes. Next, all remaining transcripts were coded by two independent coders (site coder and master coder) using codes from the established master codebook. The master coder reviewed all 7 coded transcripts and assessed agreement. Disagreements regarding codes were handled using established norms within qualitative research of using discussion to reach consensus (Saldana, 2016). The coders discussed any discrepancies through multiple web-based teleconferences, refined the codes and categories based upon those discussions, and synthesized the categories, if needed, in the master codebook. This iterative process was repeated for each transcript. Therefore, new codes were continually checked against the codebook and the master codebook was updated accordingly. The first author, and master coder, was responsible for adding new codes and distributing codebook updates across the sites. In order to maintain rigor and trustworthiness throughout the coding process, at least one of the coders was present at the focus groups at their respective sites and used notes from the focus groups to provide context for any new codes.

In order to generate themes and sub-themes, we used analytic strategies for focus group data analysis described by Krueger and Casey (2014). We examined the number of times a concept was mentioned and participants' perception of their importance by extracting semantic codes with combined frequencies (across sites) of more than seven to make sure that the concept was emergent in all seven focus group discussions. Table 4 provides the frequencies of semantic codes based on coded text segments. The original 155 codes were condensed into 85 combined or truncated codes based on combined frequencies. Finally, based on similarities under broader categories of Manifestations of BI, Impact of BI, and Strategies to manage BI, results were organized into the themes and sub-themes described below.

Results

Overall, caregivers and clinicians reported similar issues and concerns related to BI. The most common codes related to children being inflexible over the way the things must be done, and responding aggressively or with self-injurious behavior when BI was restricted. Both caregivers and clinicians agreed that BI may improve or worsen with age depending on the situation, and that children are able to be flexible at times. Caregivers also reported the importance of maintaining routine and structure for their children and their own need to be flexible to help their child.

Themes were identified across transcripts under the larger domains of manifestation, impact, and strategies used to address BI. For each theme, a series of *sub-themes* also were identified. Table 5 illustrates the findings from the focus groups. The themes generated by caregivers and clinicians revealed very similar patterns across all four domains. The strategies for measurement of BI was particularly highlighted by the clinicians. Further, no differences emerged in the frequency of codes or themes from the focus group of caregivers of girls with ASD.

Manifestation of BI.

All focus group participants clearly identified how BI manifested in daily life. The most notable manifestations of BI were related to issues of consistency, environmental changes or transitions, inflexibility in action and cognition, and variability of BI.

Consistency issues.—Many of the children described as being inflexible shared a need for consistency. This manifested in their interactions with toys, such as having the same toy accompany them during bed time; other objects, such as using the same utensils for each meal; clothes, such as insisting a favorite t-shirt be worn at all times regardless of time of day or season; or food, such as consuming only a limited number of food items. Although there was some variability in how much of a challenge these consistency issues posed for families, most parents were able to articulate concrete ways in which their child was inflexible. It is also noteworthy that some of these consistency issues, especially related to texture of food or material of clothing are related to sensory inflexibility and the inability to tolerate certain sensory stimuli.

Environmental changes.—Another manifestation of BI for many children was associated with any sort of environmental change. These included such examples as the furniture in a classroom being rearranged, taking a different route from home to school, or the presence of a substitute teacher. One mother even described her child as becoming agitated when they happened to “bump into” the child’s teacher in a community setting. The caregivers believed that when there was any deviation from a schedule and unexpected or unanticipated changes in the environment, their children’s inability to adjust in these situations often led to such behaviors as agitation, repetitive questioning, increased anxiety, or in some cases tantrums, violence, or self-injurious behaviors. The clinicians agreed with this assessment. For this reason, many caregivers and clinicians noted that transitioning from one activity to another, or one context to another was hard for their children, as well as challenging to manage.

Inflexibility in action and cognition.—All participants described common ways in which children’s actions were inflexible. These children engaged in a very limited range of activities and play scenarios, often due to their restricted interests or engagement in other types of repetitive behaviors, such as lining up toy cars. However, many also noted inflexibility in cognition that appeared to accompany inflexibility in action. For example, caregivers discussed their children’s inability to problem solve, or being able to come up with alternate solutions to a problem. One mother noted that if her teenage son with autism was unable to find a certain brand of laundry detergent in the grocery store that was on his list of things to purchase, he would not be able to problem solve with respect to either asking for assistance or choosing a different brand that was available. Additionally, caregivers and clinicians reported they believed children’s inflexibility in cognition also contributed to their having limited or no regard for others’ perspectives, which negatively affected their children’s social engagement with others. One of the mothers said, “one of the things that I get really concerned about is that’s one of my son’s strong deficits: a lack of insight”.

Variability of BI.—A final sub-theme related to the manifestation of inflexible behaviors was variability in how it was expressed over time. For some children, BI got better with age, but for some others, it did worsen over time. Similarly, some caregivers and clinicians noted a decrease in BI with children’s increase in language ability, while others noted that language simply gave the child the ability to verbalize their anxieties related to change or aspects of inflexibility. All focus group participants agreed, however, that BI changes over time and varies based on situations. For example, some caregivers described extremely inflexible children’s abilities to be flexible in certain contexts but not in others. One mother remarked, “…my daughter is inflexible almost in every area … unless it’s something super-fun that just gets thrown in the day.”

Impact of BI.

The most salient feature of BI according to parents and caregivers was that it is pervasive and impacts almost every aspect of their lives. Inflexible behaviors were identified as occurring across activities, contexts, and social scenarios. For example, one mother stated, “My daughter’s inflexible every way… because of her behaviors… it affects us in every way with different things”. As a result, many parents noted the importance of recognizing that, “everything takes extra time”.

The overall impact of BI on families and everyday family functioning was portrayed as having both negative and positive outcomes. The negative impact on child and family related to increased stress/anxiety for the child and/or the caregiver, poor academic outcomes for the child, restricted family outings, and restricted or limited interests leading to poor social relationships for the child. In contrast, the positive impact of BI was related to increased family flexibility, having structure and predictability in place, and higher levels of acceptance and tolerance from all members of the family.

Negative impact on child and family.—Participants identified both situational and ongoing stress as one of the outcomes of having a child with inflexible behaviors. For example, a child’s constant repetitive questioning led to anxiety-provoking behaviors for the rest of family. One mother noted,

> He doesn’t have tantrums much anymore, although we’ve seen a few lately ‘coz of anxiety, but repetitive questioning…Yeah, like constant, “Mom, Mom, Mom,” and then he’ll ask the same question. Eventually, I have to say, “I gave you the answer. We’re not talking about this anymore.” But there’s a point where he’s causing me anxiety.

Additionally, both caregivers and clinicians expressed other concerns they contributed to children’s inflexibility, such as disruptive behaviors and poor classroom attention that resulted in unfavorable academic outcomes. For example, some parents expressed concern that their children were having to withdraw or dropout of certain classes due to their inflexible behaviors. Additionally, in both home and school contexts, a child’s limited play and conversational repertoires led to few or no social connections or relationships with peers. As a result, highly inflexible children had fewer opportunities to participate in team sports or group play activities. Not only was this noted to be detrimental for the child’s social-emotional development, but it also had an emotionally devastating effect on the parents. One mother articulated this as a potential reason for her son being bullied. She said,

> I think that inflexibility with peers is just socially devastating because it’s
>
> just…When he’s out with his peers, and that inflexibility kicks in, it’s just like a knife in your heart cuz you just want for them to go up and say, “Hi,” but they don’t share or do that whole thing. It’s just devastating, and it opens them up to bullying…

The pervasiveness of BI in these families’ lives, accounting for extra time to complete even the simplest of tasks, and limited child interests impacted the families’ ability to engage in meaningful family activities like going to restaurants, concerts, sporting events, or taking family vacations. One mother commented on their family’s ability to eat at a restaurant. She said, “every time you go to a restaurant, it has to be Italian. It has to be—and so she’s starting to have some interest, but she still has that—she still has a really hard time”.

Similarly, when discussing the sort of extensive planning involved with taking a family vacation, one mother stated,

> …it’s very difficult for her to go to other situations. Even vacation, it’s just not even worth it for us because then you’re spending money, and the whole time you’re more stressed out than if you were at home. It’s just really not even worth it. Over the years… it just became not worth it so much to do things like that.

Caregivers also described the balancing act of wanting to support their other children by attending important activities, such as their sporting events, but recognizing that it was hard for their inflexible child to attend such events. Many times, one parent would attend the event while the other stayed home; thus, missing out on an opportunity to engage in a meaningful family outing together. Parents summed up this discussion on the family and social impact of BI when they noted their willingness to avoid social situations altogether to avoid anxiety-provoking and unpredictable situations for their child with ASD.

Positive impact of BI.—In response to BI, many families maintained strict routines so that unexpected changes would be kept to a minimum. While this was a difficult process for some families, especially while caring for multiple school-aged children, families also identified the importance of having structure and predictability as a positive outcome. Parents noted that once the routine was established, they started to view BI as the norm. Many described it as the “new normal”, stating, “it just becomes the new normal, and that’s part of what you do”. Others described the structure they maintained as a coping strategy, stating, “predictability is good”.

Caregivers also discussed their families’ ability to be flexible as a response to their inflexible child. In fact, one mother described her child with autism reacting to her other child with autism in a more flexible manner. She said,

> …our family, we’re so flexible to (child’s) needs because she is so inflexible. I have four children. Two of ‘em are on the spectrum, but even my oldest who is also on the spectrum—he’s 13—knows that when (child) says this is what she wants, unless we want full meltdown, we’re going with what she wants.

This accommodation and ability of the family as a whole to be flexible was noted as a positive impact of BI. Additionally, caregivers found that their experiences with an inflexible child led to them having increased levels of acceptance and tolerance towards others. One mother stated, “I think it teaches compassion. If I’m in a restaurant, before I had my child, I’d be like (sigh)…Ok, this child has something going on. I’m not even gonna worry about it”. The same mother noted that her other children that were not on the spectrum also developed a sense of compassion and patience with respect to other children that may have a disability.

Strategies to address BI.

Caregivers and clinicians both emphasized the importance of maintaining structure and having a predictable routine as valuable strategies to address BI. Additionally, when multiple people were working with the child, having everyone "on the same page", and adhering to the routine also was described as an effective way to manage BI.

Multiple strategies.—Most caregivers and clinicians stated that they almost always used more than one strategy to manage BI. For example, becoming more flexible as a family to accommodate the inflexible child, always having a plan and a back-up plan, preparing the child for upcoming events, and keeping everyone in the loop about ongoing activities, are just some of the ways that caregivers and clinicians address BI. Parents also described relying on other family members to help manage BI. One mother said, "we rely so much on the two kids not on the spectrum to help the two kids that are on the spectrum".

Maintaining structure.—Caregivers and clinicians both described the use of visual schedules as a helpful tool for maintaining a consistent routine. This consistency prevented meltdowns related to the child's BI. Additionally, maintaining consistency seemed to reduce stress and anxiety for both the child as well as caregiver since they knew what to expect. Having a consistent routine also made it easier for multiple people working with the child to "be on the same page".

Having a plan.—Similar to maintaining structure, having a plan, and sometimes a backup plan aided in maintaining a consistent routine for the child. Additionally, preparing the child beforehand as well as making all people involved aware of the plan helped the caregivers to avoid tantrums or meltdowns related to BI. For some parents, planning vacations for months in advance in order to prepare the child for what was to come became an effective way to circumvent the negative impact of limited family activities. For example, one mother began taking her son on "field trips" to the airport to see planes take off and land to prepare him for an upcoming flight. However, for other caregivers, avoiding certain situations, such as going grocery shopping, became the coping strategy of choice.

Summary of results.

Although divided into themes and sub-themes for ease of presentation, it is important to note that many scenarios described by the caregivers and clinicians overlapped and had implications for more than one aspect of their lives. For example, variability of BI in relation to language development could be described under the sub-theme of "variability in BI" as well as "inflexibility in cognition". In general, across themes and subthemes, we found that BI was extremely prevalent across all domains of everyday activities. The findings provide further evidence that BI is a pervasive part of the daily lives and activities of children with ASD and their caregivers.

Salient differences between caregiver and clinician perspectives.

Although caregivers and clinicians expressed many similar concerns and insights regarding the overall impact, manifestation, as well as strategies to manage BI, one significant difference was noted in the discussion of how to measure BI. Since these opinions were primarily voiced by clinicians and not as strongly emphasized by caregivers, *measurement* did not emerge as a theme or sub-theme as a result of our analysis. However, it is worth noting that the clinicians that participated in the focus groups were actively concerned about how BI should be measured. The main idea voiced was that the measurement of BI should be subjective; although it potentially could be captured using such metrics as frequency counts of inflexible behavior or recording the duration of time it takes for the child to adapt, ultimately, BI impacts each child and family differently. This corroborated our findings from the caregiver focus groups as well. Caregivers also believed that what may be a problem for the family on one day may not be a significant problem on another day due to changing contexts or accommodation strategies put into place by family members. Thus, the general consensus among the clinicians was that a subjective measure of BI would be most appropriate in order to understand the needs of each family uniquely.

Discussion

Our findings suggest that caregivers’ and clinicians’ view BI as an important construct that manifests in multiple ways to affect the daily lives of children with ASD and their families. Caregivers and clinicians reported the impact of inflexibility on multiple areas of children’s development (e.g., social, play); that occurs across contexts including home, school and community; and effects the entire family in both negative and positive ways. While caregivers and clinicians reported similar issues and concerns, some of the most common themes touched on BI being pervasive but highly variable, and the need for the family to be flexible when the child cannot. In this regard, the focus groups were particularly influential in revealing the impact of BI on families and the extent to which caregivers and clinicians have to accommodate BI in daily life. Finally, the discussion of BI as changing over time and with the use of certain strategies suggests that it is amenable to treatment.

Our focus groups further highlighted the duality of inflexibility – affecting both behavior (e.g., RRBs and social communication) and cognition as well as having both positive and negative consequences. While previous research has focused on cognitive inflexibility in ASD, this work often included only individuals without co-occurring intellectual disabilities (Kaland, Smith & Mortensen, 2008; Strang et al., 2017) and/or was more mechanistic in nature (Dajani & Uddin, 2015; Sanders, Johnson, Garavan, Gill, & Gallagher, 2008). While parents and clinicians certainly alluded to, and in some cases outright acknowledged that their children had issues with executive functioning, they more so focused on how inflexibility in thought expressed itself during everyday occurrences in a variety of domains. For instance, parents spoke of their child’s inability to play differently or engage in a task differently even when shown an easier way. Parents and clinicians believed that this inflexible thinking, or perhaps in some cases rumination, contributed to their child’s stress and anxiety, often exacerbating manifest inflexible behavior or leading to other behavioral outbursts. This finding was not surprising, as several studies have shown a link between insistence on sameness and anxiety (c.f.e. Joyce et al., 2017; Rodgers et al., 2012). Even though anxiety was not a salient theme nor the focus of this study, although some parents did raise this issue, it is possible that anxiety either leads to or is a consequence of BI, and it is also possible that anxiety could have both negative and positive relationships to BI. For example, engaging in inflexible behavior may help some children cope with their anxiety just as it has been found that engaging in motor stereotypies may serve a homeostatic function (Repp, Karsh, Deitz, & Singh, 1992).

Our focus group findings in some ways mirror other research on repetitive behaviors with both positive and negative impacts of BI reported by parents. In particular, circumscribed interests that are often viewed as both a source of strength or special ability for the child but also potentially limiting social interaction with others (Klin et al., 2007; Mercier et al., 2000) were evident. Interestingly, for families, the positive impacts of BI often had to do with how they had to change and be more flexible in order to accommodate how inflexible the child was. In many ways the child being inflexible was simply considered the new normal and families often had trouble separating out if the accommodations they had put into place were helping the child, as those accommodations often involved avoidance of situations that may evoke inflexible behavior. Without hearing the personal perspectives of parents, we may not have fully considered that a child being inflexible could be viewed in a positive light. In fact, the positive adaptive benefits of BI may also be evident for the children with ASD themselves. For example, intense interests could lead to areas of expertise and provide avenues for shared interests with other people; as stated, motor stereotypies may reduce anxiety; and as highlighted by the caregivers, predictable routines can enable independence in the child. These interpretations are consistent with the resiliency interpretations of RRBs (Cho et al., 2017; Maloret & Scott, 2017; Smerbeck, 2017), and also may be the case with BI, specifically. This also speaks to the importance of understanding the impact of inflexibility on both the child and family.

There were at times seeming contradictions in how caregivers discussed BI; for example, on one hand, caregivers talked about the importance of maintaining routine and structure for their children, while on the other hand, they talked about the family’s need to be flexible in order to support the child. In this regard, it would be worthwhile to consider conducting follow-up semi-structured interviews with individual families in the future as an addition or alternative to focus groups, as those might yield more insight into some of these opposing views. While seemingly contradictory, in both instances, parents are often maintaining structure yet being flexible to prevent the child from having meltdowns, get through the day, and preserve family order. While the family’s daily routines may begin to center around the child’s needs, previous research has emphasized the importance of maintaining routines and rituals to create a sense of belonging and self-efficacy for families of children with and without disabilities for the promotion of family functioning and well-being (Boyd, McCarty, & Sethi, 2014; Downs, 2008; Evans & Rodger, 2008; Koome, Hocking, & Sutton, 2012).

Finally, the use of qualitative methods presents both strengths and limitations for the current study. In this case, focus groups and subsequent thematic analysis of the data provided a means to obtain the perspectives of a diverse group of parents and clinicians on a wide age range of children. In qualitative research, having such a heterogenous group can lead to higher levels of transferability (i.e. analogous to generalizability in quantitative research) of results. This is informative for both defining and beginning to clinically address issues of BI. Parents’ and clinicians’ real-life examples of how the child’s inflexibility impacted them provided useful insight to understand how inflexibility changes over time, manifests across contexts, and is pervasive in the sense that it impacts multiple aspects of the child’s functioning and family life. All of this suggests that BI would be a meaningful treatment target. Another strength is that we had a focus group solely focused on parents of girls on the spectrum aligning with wider research priorities to understand the female phenotype and experience in ASD. While no major differences emerged between the parents in this focus group and the others, we now have a sense that BI has no clear gender boundaries.

Limitations.

Study limitations include the use of focus group methodology. Even with ground rules in place to encourage confidentiality and participation by all focus group members, there were certainly times when specific members of the group talked more and perhaps overly shaped the opinions of others on a given topic. An additional limitation is that our focus groups occurred at one point in time and since parents and clinicians told us that children's inflexibility changes over time, it would have been helpful to have repeated discussions to try to capture any resultant changes in parent and clinician perceptions as their children's level of inflexibility improved or worsened. Still the collection of data from a single time point with such a wide age range of children (ages 2 – 17) provided insights into BI as a developmental phenomenon, as most parents and clinicians discussed how children's inflexibility had changed over time.

All caregivers were referred to the study via university/clinic registries that require a clinical diagnosis of ASD. As our study focused on caregiver insights, we did not confirm the child's diagnosis via gold standard diagnostic tools. Instead, all caregivers completed the SCQ-Current to provide an index of their child's current ASD symptoms. However, the validity of the SCQ, particularly the current version, has been questioned for older individuals and/or those without co-occurring cognitive impairments (e.g. Barnard-Brak et al., 2016; Eaves et al., 2006; Marvin et al., 2017). This was reflected in the high number of individuals (particularly female) who fell below the cut off for ASD and non-ASD specific developmental delays. Additionally, the recruitment strategy resulted in almost 60% of the sample with an annual household income of over US$90,000. Two potential reasons we ended up with a higher income sample are (1) the use of university-based, participant registries as certain types of families may be more likely to sign up for participation in research studies; and (2) families had to be able to travel to the clinical site; thus, families who did not have access to transportation would have been unable to participate. Future studies should target families from lower household incomes to ensure findings are representative of more families of children with ASD.

Finally, while this study focused on parent and caregiver perspectives, first person accounts were not collected. Since Joyce et al (2017) have shown that some young people with ASD (aged 10–17) are able to reflect upon and discuss their own RRBs, future studies with their accounts could bolster or refute our findings. We focused on caregivers and clinicians because we anticipated that with such a broad range of children, in terms of age and cognitive ability, some would not be able to participate in interviews and we wanted to also understand the perspectives of families with younger and/or less verbally able children.

Implications for future research

Although generalization of results is not a goal of qualitative research, the inclusion of clinicians and parents of children across a wide age range and ability level in our focus groups could optimize the transferability of these findings. Future research could include parent and/or clinician perspectives related to inflexibility for children with other neurodevelopmental disorders, such as Down or Fragile-X syndrome, to understand parallels and differences with ASD. This would also inform whether different treatment modalities would need to be developed for these populations.

Additionally, our focus groups represent the first in a series of steps toward the development of an outcome measure that can capture the functional impact of BI and how it changes as a function of targeted treatments. Focus groups are becoming an increasingly common method used in outcome measure development in order to ensure developed measures have face validity and measure the construct of interest in a way that is meaningful to, and representative of, the targeted population (Lasch et al., 2010; Patrick et al., 2007). Although more work is needed to develop an outcome measure for BI in ASD, the current study demonstrates that this understudied and under-developed construct is important to families and would represent a meaningful treatment target. The findings from this study further suggest that an intervention might not need to diminish BI, but rather enhance the natural processes and strategies many parents are already using to adapt and accommodate the child’s BI. This reinforces the idea that facilitating adaptation and acceptance of BI by family members could be as important as providing strategies to decrease BI when it presents challenges.

Acknowledgments

Funding: Research reported in this publication was supported by the Eunice Kennedy Shriver National Institute Of Child Health & Human Development (R01HD082127 and P30-HD03110). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Portions of this data have been presented at the Gatlinburg Conference of Intellectual and Developmental Disabilities 2017 (San Antonio, TX), and the Society for the Study of Occupations: USA Annual Conference 2016 (Ft. Lauderdale, FL). We thank the families whose participation made this study possible.

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Table 1:

Caregiver Demographics (N = 30)

Caregivers		
Mother:Father		27:3
Caregiver Age (Years)[*]		40.2 (8.34)
Ethnicity	Not Hispanic/Latino	30
	Hispanic/Latino	0
Race	White	20
	Asian	2
	African American	7
	Not reported	1
Education	High School Graduate	2
	Some College/Post High School	7
	Bachelor’s Degree	9
	Graduate/Professional Degree	11
	Not reported	1
Household Income in USD	$20,001 - $40,000	3
	$40,001 - $60,000	5
	$60,001 - $90,000	4
	More than $90,000	17
	Not reported	1
Children		
Child Gender (Male:Female)		17:13
Child age (Months)[*]		99.13 (60.78)
Ethnicity	Not Hispanic/Latino	28
	Hispanic/Latino	2
Race	White	20
	Asian	2
	African American	7
	Not reported	1
Type of education placement	Public School/Kindergarten/Preschool – Regular Classroom	13
	Public School/Preschool – Special Classroom	4
	Private School/Preschool – Regular Classroom	3
	Charter School	1
	School for Children with Developmental Disabilities	8
	Other	1
SCQ Total Score[*]		16(8)
Siblings with ASD diagnosis (yes:no:not applicable)		7:17:6

[*] where applicable = mean (SD)

Charter School is a publicly funded independent school established by teachers, parents or community groups in the US.

Table 2:

Clinician Demographics (N = 25)

Gender (Male: Female)		**5:20**
Occupation	Behavioral Therapist	3
	Clinical/School Psychologist	3
	Speech and Language Therapist	8
	Occupational Therapist	2
	Teacher	3
	Psychiatrist	2
	Teaching Assistant	2
	Other	2
Education Level	Bachelors Degree	5
	Master Degree	11
	Higher/Professional Degree	9
Years experience in profession *		16.83 (12.72) (1 *not reported*)
Years experience with child/adolescents with ASD *		13.27 (6.83) (1 *not reported*)
Ethnicity	Not Hispanic/Latino	24
	Hispanic/Latino	1
Race	White	24
	African American	1

*Where applicable = mean (SD)

Table 3:

Example questions from caregiver focus group guide

• Does your child display inflexible behaviors? If so, how often does he/she display these behaviors? Possible follow ups: – Can you give us one or two examples? – Under what circumstances does your child display these behaviors? i.e. what triggers these behaviors?
• How does your child's behavioral inflexibility impact him/her? For example how does it affect their ability to interact with peers? Complete school work? Their ability to regulate themselves?
• How does your child's behavioral inflexibility impact family life? Possible follow-ups: – Are there any adjustments you have to make to deal with your child's inflexibility? Examples?
• Has your child's behavioral inflexibility changed over time? If so, how? Frequency, triggers, intensity? Possible follow-up: – Why do you think these behaviors have changed? (coping strategies, intervention…)

Table 4:

Code Concept and Select Semantic Codes with text examples

Code Concept	Semantic Code Example	Quoted example from Focus Group text	Number of coded segments
Impact	BI as pervasive	“the whole family’s got this thing going on now”	149
	BI impacts community outings/ travel	“we can’t go to the store, or we can’t go to a movie, we can’t go to a new restaurant, we can’t go on vacation, we can’t—it’s like we’re prisoners in their own home”	62
	Family accommodates BI	“our fawmily, we’re so flexible to (child) needs because she is so inflexible”	129
Manifestation	BI as need for sameness	“whether it’s certain colors and cups; or certain ways you cut things…it always has to be red”	116
	Variability in BI	“Just because they’re one way at 3 and another way at 10 has almost no bearing on how they’re gonna be at 14, at 17, and 23”	134
	BI as inflexible information processing	“It’s the way my son processes things”; “She asked the same question about traffic like six times before it clicked in her head, and she’s like, ‘Okay, traffic.’”	60
Strategies	Prepare/coach child and others beforehand	“Usually, coaching beforehand helps; We’re gonna prep him, like, ‘Yeah, we’re gonna go to this store. There’s gonna be toys there, but you can only look. We’re not gonna be buying anything. You can enjoy the toys, but we have to leave ‘em there.’”	111
	Control and/or avoid situations	“We have to limit him going to the store cuz he’ll literally, with the cart, stand there and look through”; “That’s probably where I’ve adapted to his inflexibility is avoiding situations altogether”; “rather than fight with him and trying to get him into a social realm of haircuts at a store, it was easier to just cut his hair at home”	57

Table 5:

Focus Group Findings

Domain	Basic Theme	Sub-Themes
Manifestation of BI	Consistency issues	Consistency with objects, play scenarios, foods, etc.
		Consistency with environments/transition issues
		Sensory issues
	Inflexibility in action and cognition	Inflexibility of thought/inability to problem-solve
		Disregard for others' perspectives
		Restricted interests
		Restricted engagement in activities
	Variability in BI	BI changes over time
		BI inconsistent based on situation
		Variability of BI with language skills
Impact of BI	Negative impact on child and family	Child/caregiver stress/anxiety
		Poor academic outcomes
		Poor social relationships
		Restricted community outings
		Child's limited activities
	Positive impact on child and family	BI as norm
		Increased family flexibility
		Increased acceptance and tolerance
		Structure as a coping strategy
Strategies to address BI	Multiple strategies	Maintaining structure
		Having a plan