



Repetitive behaviors: Listening to the voice of people with high-functioning autism spectrum disorder



Iris Manor-Binyamini^{a,*}, Michal Schreiber-Divon^b

^a The University of Haifa, Special Education, Mount Carmel, 31905, Haifa, Israel

^b Talpiot College of Education, Yotveta 7, Holon, 58500, Israel

ARTICLE INFO

Keywords:

Repetitive behaviors
People
Autism Spectrum Disorder
Perspective

ABSTRACT

This study examined how people with high-functioning autism spectrum disorder (HFASD) perceive and explain their own repetitive behaviors. Despite the wealth of knowledge on repetitive behaviors in HFASD, there are few studies on repetitive behaviors from the perspective of adults with HFASD. Here, data were collected from semi structured, phenomenological interviews with 16 adults (aged 35–55 years) with ASD. The findings indicated four main reasons for repetitive behavior: enhancing the ability to function; reducing external stimuli and avoiding communication; coping with stress, distress, and excitement; and coping with social communication.

Conclusion: The findings suggest that repetitive behaviors play a functional role in people with HFASD and also serve as a way for these individuals to cope with their environment.

1. High-functioning autism spectrum disorders in adults

Autism spectrum disorders (ASDs) are developmental disorders characterized by an impairment of reciprocal communication and social interactions and the presence of restricted stereotypical behaviors and interests (American Psychiatric Association, 2013). According to a recent epidemiological study (Lyall et al., 2017), ASD affects 1% of the adult population worldwide and appears to be increasing. As more children are diagnosed, it makes sense that the emerging adult population with ASD will also continue to grow. In contrast to the considerable research in children with ASD, the literature on adults with ASD is sparse. Therefore, there is a critical need for more research on adults with ASD (Interagency Autism Coordinating Committee, 2011). In particular, a better understanding of the strengths and weaknesses of adults with ASD is needed to inform the development of support and services. One of the difficulties faced by adults with ASD is repetitive behaviors (RRBs).

2. RRBs: lower order and higher order

RRBs are a core feature/criterion of ASD and represent a heterogeneous class of behaviors. RRBs are now understood to be a continuum of behaviors that serve various functions throughout development and vary based on skill acquisition and mastery level (Uljarevic et al., 2017). These include atypical sensory behaviors such as hyper-/hyporeactivity to sensory input or unusual interests in sensory aspects of the environment and an insistence on sameness in the environment (American Psychiatric Association, 2013). Distinctive subclasses of RRBs have been identified in ASD (Leekam, Prior, & Uljarevic, 2011). For example, molecular genetic

* Corresponding author.

E-mail addresses: iris.manorbinyamini@gmail.com (I. Manor-Binyamini), schrmichal@gmail.com (M. Schreiber-Divon).

<https://doi.org/10.1016/j.rasd.2019.04.001>

Received 28 March 2018; Received in revised form 14 February 2019; Accepted 1 April 2019

Available online 09 April 2019

1750-9467/ © 2019 Elsevier Ltd. All rights reserved.

Turner (1999)	Lower Order RRBs			Higher Order RRBs		
RSM and IS terms (Richler et al., 2010)	Repetitive Sensory Motor (RSM)			Insistence on Sameness (IS)		
Lam & Aman (2007) RBS-R Algorithm	Self-Injurious Behavior	Stereotyped Behavior	Restricted Behavior	Compulsive Behavior	Ritualistic/Sameness Behavior	
Bodfish et al. (2000) RBS-R Algorithm	Self-Injurious Behavior	Stereotyped Behavior	Restricted Behavior	Compulsive Behavior	Ritualistic Behavior	Sameness Behavior
Mirenda et al. (2010) RBS-R Algorithm	Self-Injurious Behavior	Stereotyped Behavior and Restricted Behavior		Compulsive Behavior, Ritualistic Behavior and Sameness Behavior		

Fig. 1. Results from factor analyses of RRB subtypes.
Adopted from [Thurm et al. \(2013\)](#).

evidence points to symptom-specific genetic effects related to high levels of RRBs ([Sutcliffe et al., 2005](#)), and RRBs are thought to represent different neural pathways ([Langen, Kas, Staal, van Engeland, & Durston, 2011](#)). Such different neural pathways are new ideas, and evidence is emerging from neurobiology and developmental psychology that identifies neural adaptation, lack of environmental stimulation, arousal, and adaptive functions as key factors in the onset and maintenance of RRBs ([Leekam et al., 2011](#)).

RRBs are considered to interfere with social adaptation (e.g., [Loftin, Odom, & Lantz, 2008](#)) and are also associated with anxiety in people with ASD (e.g., [Lidstone et al., 2014](#)).

The literature places RRBs on a continuum from higher-order to lower-order behaviors, with higher-order behaviors considered as more specific to the ASD population, whereas lower-order behaviors apply to a wider range of populations, with and without special needs, including people with ASD ([Thurm, Farmer, & Shumway, 2013](#)). Lower-order RRBs are characterized by repetitive sensory motor movements, and higher-order RRBs are more complex and include insistence on sameness. Factor analyses of one commonly used measure of RRBs have found various factor solutions describing RRB subtypes ([Fig. 1](#)).

Low-level/repetitive sensory motor behaviors include repetitive motor stereotypes, such as hand flicking and body rocking; stereotyped or repetitive vocalizations; repetitive actions with objects such as spinning wheels; and repetitively opening and closing containers as well as sensory-seeking behaviors, such as close visual examination of objects and mouthing or licking objects. High-level activities encompass behaviors such as intense and restricted interests, ritualized behavior patterns, excessive adherence to routines with significant resistance to change, and the rituals and routines that encompass IS behaviors ([Thurm et al., 2013](#)).

Researchers have found associations between the type of RRB and mental capacity, where higher-order RRBs were observed to a greater extent in higher-functioning individuals and lower-order RRBs were associated with lower mental abilities. Further studies have reported relationships between the existence of mental disabilities and certain RRBs ([Cervantes, Matson, Williams, & Jang, 2014](#)) and between other repetitive patterns and an average or higher mental capacity ([Faja & Darling, 2018](#)). In contrast, other studies have shown that RRBs were more closely related to an ASD diagnosis than to the existence of an intellectual disability ([Gal, Dyck, & Passmore, 2009](#)).

Recent research suggests that RRBs in particular can vary across cultures and that cultural norms may play a significant role in how parents perceive the atypicality and severity of RRBs ([Matson et al., 2017](#)). For example, in a survey on ASD symptomatology, Polish parents more frequently cited restricted interests, whereas US parents more frequently mentioned repetitive motor movements, and Greek parents mentioned items relating to routines ([Matson et al., 2017](#)).

2.1. RRBs: point of view of adults with high-functioning ASD (HFASD)

In recent years, there has been an increase in the frequency of ASD diagnosis worldwide ([Neggers, 2014](#)) and with it, an increase in the publication of studies focusing on ASD in a variety of different disciplines. Despite the growing data from ASD research, there are few ASD studies using first-person interviews, although individuals on the autism spectrum are both linguistically and mentally

capable of sharing their experiences, thoughts, and opinions. Over the years many reports of people with ASD have been published in the form of autobiographies, movies, or online blogs (Shore, 2001; Williams, 2007). Most individuals with ASD indicate that they feel that although their environment expects them to understand the complex rules of the world, no attempt has been made to understand them and their world, their language, or their perceptions. Accordingly, no effort has been made to adapt the environment to their needs and behavioral capabilities. The scant qualitative research on the characteristics of ASD nevertheless highlights that the main difficulties are related to regulation and differences in processes of perception and information processing. Jones, Quigney, and Huws (2003) examined online publications written by individuals who presented themselves as HFASD and found that their perceptions of their sensory behaviors were that these behaviors functioned as a source of pleasure as well as a way to cope with difficulties and experiences of distress and discomfort. Results from studies that have interviewed people with ASD also suggest that these individuals perceive RRBs differently. In an autobiography published by Prince-Hughes (2002, p. 13), the author described an incident with one of her elementary school teachers that emphasized the gap between the external perceptions of others and her own inner experience regarding stereotypical movements: “He told me not to do it, and I remember that I couldn’t understand why I couldn’t jump, which was so calming to me. I had long ago decided to stop performing in public some of the behaviors stereotypical to ASD and would do them only in my room. That was the last time.”

Davidson (2010) analyzed 45 autobiographical writings by individuals with ASD, in an attempt to understand how they perceive sensory stimuli. He indicated that the authors state that these “unexplained” stereotypical ASD movements, such as swaying, waving one’s arms, or humming, are aimed at providing a rhythm so that access to the world is easier and more understandable and that these movements create a stable, less threatening sensory environment.

Thus, overall, little is known about the subjective experience of RRB and the reasons for these behaviors in the opinion of individuals with HFASD. This type of research is nevertheless crucial, since studies have shown that there are gaps between perceptions of ASD characteristics in the literature and the experiences of people with ASD. The purpose of the current study was to examine how people with ASD explain and perceive their own RRBs.

3. Method

To examine the experiences and perceptions of adults with ASD with regard to RRBs, a phenomenological approach was used. This approach enables the systematic learning of a complex and multidimensional phenomenon, which by nature is difficult to measure from the subjective point of view of the person who experiences it (Creswell, 2007). The phenomenological method allows the researcher to focus on the processes and meanings that the experience represents to those who experience it and its place in their everyday lives (Creswell, 2007). In addition, the phenomenological approach focuses on the individual and uses an inductive procedure (Laliberte-Rudman & Moll, 2001).

3.1. Sample

Sixteen adults aged 35–55 years were interviewed for this study, all of whom had been diagnosed in childhood with ASD according to *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition, criteria and the National Health Care Law (Ministry of Health Director Circular 15/2013) by a psychiatrist. Most were characterized as HFASD. As shown in Table 1, 75% ($n = 12$) of the participants graduated from high school, and 25% ($n = 4$) had a degree from an institution of higher education. More than half, 62%, were living in a hostel (in Israel, hostels are a framework for people with HFASD within the community; $n = 10$). Approximately half were living with a spouse (56%, $n = 8$), and the rest were single.

The selection criteria were a previous diagnosis of autism, high verbal functioning that enabled their participation in the interview (defined as HFASD), no intellectual disabilities, no history of other neurological disorders, and no history of major mental

Table 1
Demographic Characteristics of the Study Participants.

Interview Number	Age/Gender	Education	Source of Income	Marital Status
1	35/M	High school	Welfare	Spouse
2	55/M	High school	Allowances	Single
3	44/M	Higher education	Allowances	Single
4	52/M	High school	Allowances	Spouse
5	50/M	High school	Factory	Merited
6	49/F	High school	Factory	Spouse
7	38/M	Higher education	Allowances	Single
8	40/M	High school	Factory	Spouse
9	43/M	High school	Allowances	Single
10	45/F	High school	Allowances	Spouse
11	39/F	High school	Factory	Spouse
12	55/M	Higher education	Allowances	Single
13	60/M	High school	Allowances	Spouse
14	42/F	High school	Allowances	Spouse
15	40/M	High school	Factory	Single
16	55/M	Higher education	Allowances	Single

Table 2
Social Functioning in Adults with ASD.

Social Function	Adults with ASD (N = 16)	
	M	SD
SRS social cognition *	60.11	6.83
Social communication	63.38	7.53
RRB: Restrictive interests and repetitive behavior	61.27	5.58

* Note that the Social Cognition, Social Communication, and RRB subscales of the SRS measure dysfunction. Thus, lower scores indicate improved social functioning.

illness (e.g., schizophrenia). All participants were living in hostels (in Israel, hostels are a framework for housing for people with HFASD within the community, in which they live independently, with or without a spouse).

Because the participants were relatively older, and because their ASD diagnosis had been conducted many years previously, for the purposes of this study, the participants were asked to complete the Social Responsiveness Scale, second edition (SRS 2), adult version to assess social functioning. The SRS-2 was used to measure the severity of ASD symptoms and social skill functioning (Constantino, 2012). The SRS-2 is a 65-item rating scale divided into five subscales: Social Awareness, Social Cognition, Social Communication, Social Motivation and Restricted Interests, and Repetitive Behavior. Each item is scored on a 4-point Likert-type scale, ranging from 1 (*not true*) to 4 (*almost always true*). A total raw score greater than 70 is diagnostically significant, with a sensitivity of 0.78 and a specificity of .94 (Constantino, 2012). The reliability and validity of the SRS-2 is supported by internal consistency reliability ranges from 0.93 to 0.97, temporal stability estimates of $r = 0.88$, and convergent validity between parent and teacher ratings of $r = 0.72$ (Bolte, Poustka, & Constantino, 2008; Constantino et al., 2007).

For the purposes of this study, we examined the Social Cognition and Social Communication subscales of the SRS. The SRS was completed with one-on-one assistance from researchers or parents.

Table 2 summarizes the mean scores and standard deviations organized by construct of social function.

3.2. Instrument

A semi structured, phenomenological interview was conducted (Laliberte-Rudman & Moll, 2001). This type of approach is the most suitable for inquiring how individuals with ASD perceive their RRBs and the meaning they assign to these behaviors. In a semi structured interview context, the interviewee is the expert, with a great deal of valuable knowledge about the topic in question, and he or she shares this knowledge with the interviewer and helps him or her understand it (Laliberte-Rudman & Moll, 2001). In this study, the interviews were conducted face to face in a location of the interviewee's choice.

The main question guiding the design of the questionnaire was how people with HFASD perceive their RRBs that they enact in their daily lives, what these behaviors mean to them, and their implications on their functioning. The interview was based on four different types of questions (Spradley, 1979) (see Table 3).

3.3. Research procedure

After receiving approval from the Ethics Committee of the Ministry of Social Affairs, as well as the University of Haifa, hostels in the center of Israel were contacted to help recruit participants for the study. This initial request included a statement on the purpose of the study, its guarantees of confidentiality and anonymity, and ways to contact the first author. Contact was made by telephone, during which further details were provided and consent was obtained to take part in the study. Then, a date was set for the interview, in a face-to-face meeting at a location of the interviewee's choice.

Each participant was interviewed individually. To develop rapport and put the participants at ease, the researcher engaged them in conversation while accompanying them to the interview room. This conversation centered on general issues such as what the participants had been doing earlier that day and their plans for the upcoming holiday.

At the beginning of the interview, the researcher explained the topic and purpose of the study, the research procedure, the

Table 3
Interview guide.

Do you think, and if so, which behaviors affect your functioning? Your daily routine?	Focus/Centers question
I would be happy if you could help me understand, as a person who is on the outside of this, your experience. . . .	Exploratory question (expanding knowledge of phenomenon)
- Were there occasions when people with ASD or you made use of repetitive behavior?	Descriptive
- Explain to me why you used them? What led you to use these behaviors?	
Describe to me what you feel before, during, and after you perform repetitive behaviors?	Structured questions
Tell me about the way you perform repetitive behaviors. What repetitive behaviors do you perform?	
Are these behaviors daily and performed regularly?	

commitment to confidentiality, as well as the participant's right to terminate his or her participation in the study at any time. Participants were asked to sign an informed consent form. The participants were asked to fill out a sociodemographic questionnaire, and then the interview was held. Although it was not anticipated that the research would pose any direct threat, participants were also asked to identify a person whom they would want the researcher to contact should a situation of distress arise during the interview.

The interviews lasted between 30 and 90 min; all interviews were recorded and transcribed. The interviews were conducted by the first author of this study, who had many years of experience working with individuals with ASD. All interviews were conducted, transcribed, and analyzed in Hebrew. The findings were translated into English during the writing of the article.

3.4. Data analysis

During each interview, the first researcher took field notes. Immediately after the interview, the researcher completed a contact summary form describing the main thoughts and key points emerging from the interview. All interviews were then transcribed verbatim. The interviews were analyzed thematically using familiarization, highlights, and memo-writing/notetaking techniques (Burnard, 1991). The thematic analysis and thematic coding were applied using a multiple-stage procedure, in which the first step involved the interpretation of individual interviews. Data analysis consisted of procedures described by Van Manen (1990) for capturing the participants' experiences in a comprehensive, holistic way. These procedures included categorizing all the verbatim interview texts into statements. Following Van Manen's (1990) guidelines, the second researcher read each interview several times to obtain a comprehensive sense of the themes and experiences the participant was describing. The researchers continuously referred back to each transcription to discover common themes and identify relevant quotes. In the process of generalizing the themes, the second author carefully followed coding practices (Berg, 2004), with the aim of reflecting the main message of the data while maintaining the study participants' original wording as much as possible.

The researchers worked together to determine the final themes based on the imaginative variation technique (Van Manen, 1990), a process that determines the extent to which a particular theme is fundamental to the analysis. In this process, the researchers examined each theme and evaluated how the absence of the theme would affect the analysis. Each theme added a different dimension to the essential meaning of the findings. Thus, all of the initial themes were retained. To assess the reliability of the coding system, the two authors conducted a double-blinded coding of the two interviews. Narralyzer software was used to manage the data and organize the transcripts of the interviews, which were condensed in relation to explanations of RRB.

4. Results

The thematic analysis pointed to four main reasons for the existence of RRBs as cited by the ASD participants in this study: enhancing the ability to function; reducing external stimuli and avoiding communication; coping with stress, distress, and excitement; and coping with social communication.

4.1. Reason 1: enhancing the ability to function

The participants noted that the use of RRBs was helpful for enhancing their ability to function and to perform various tasks, specifically for maintaining their levels of arousal and concentration

. These included mainly "low" RRBs, such as stereotypical movements and self-harming behaviors. Many participants said the use of repetitive movements helped maintain an optimal level of arousal, attention, and concentration during learning or in other situations that require concentration and focused thinking (such as using a computer) as well as in social situations. RRBs such as repetitive walking movements, swaying back and forth, rubbing surfaces, repetitive play with an object, and making sounds were mentioned. For example:

"Sometimes it's because I feel, say I feel that things are taking too long, so, I have a way... to avoid losing my attention span. . . it helps me." (R, 5)

"I ... feel objects in my hands, intensely ... it helps me to focus my attention when I need it, say, at a lecture. It, sort of, keeps me awake ... it puts my whole body in motion, sort of...." (R, 7)

4.2. Reason 2: reducing external stimuli and avoiding communication

The participants often described hypersensitivity to sensory stimuli and in multiple sensory areas, which they experienced as something threatening. The interviewees described RRBs designed to reduce the effects of their oversensitivity to external stimuli. The participants described hypersensitivity to specific types of physical contact, which they sometimes experience as pain, leading to avoidance, such as sensitivity to soap and foam on their hands that gives them a burning sensation. For example:

"I feel under attack, I feel overwhelmed by the environment, I feel like my ears are about to explode and everything... As if my personal space was penetrated by the noise... A few months ago, at an event, there was so much noise and flashing light, I started to cry... I felt a kind of dizziness, Something like that." (R, 1)

Another interviewee described how various RRBs relieve the feeling of being overwhelmed:

“I’m constantly making gestures with my hands, it makes things easier for me, it’s a physical feeling, I try to avoid communication and reduce stimuli as much as possible.” (R, 6)

These descriptions, in which participants describe their difficult experiences with overstimulation, explain the urge participants feel to make RRBs to block troubling stimuli or reduce or avoid them. The participants also described under sensitivity to certain stimuli, which leads them to need stronger stimuli than is socially acceptable. For example:

“I hug. I need to know that the different parts of my body are activated....”

Most of the participants noted the constant need for stimulation and their search, throughout the day, for a source that provides this stimulation through repetitive movements. A number of the participants also noted that these movements are the natural state of being for them. They stated that stopping these movements requires resources and energy and causes them to search for other stimuli that include sensation or movement and to make certain repetitive movements that satisfy this need.

Other repetitive movements were described as a means of lessening sensations of pain, for example, applying deep pressure and rubbing the area of the body that is in pain. For example:

“To release the pain, I wave my hands energetically... It liberating... because otherwise I don’t feel the sensation of contact... it releases... ” (R, 3)

4.3. Reason 3: coping with stress, distress, and excitement

Many participants described the use of repetitive movements as a way of relieving tension in emotional situations that are difficult for them, such as stress and excitement. In these kinds of situations, the participants described shaking an area of their body, such as a leg, swaying repetitive movement through space, such as walking from side to side, playing with objects in their hands, and so on. All participants noted that in periods of their life that are characterized by high stress, their use of RRBs becomes more frequent and more intense than usual. For example:

“... these behaviors, they help me cope with the stress and the anxiety... but they help me even when I’m happy and when I feel really good, when I am so happy.” (R, 7)

Other participants stated that repetitive movements gave them a sense of security. These included the repetitive movement of an object in their hands, rotating the object, and holding a small object in their hands without any movement. According to the participants, repetitive movements are a familiar activity that they already know and thus, they increase their sense of security. For example:

“When I move the object that I’m holding in my hand around, over and over again... it gives me something, maybe a little safety, sort of.” (R, 2)

Another type of RRB described by the participants that constitutes a strategy for coping with stress is self-harm. The participants noted that they sometimes engage in self-harming behaviors to shift the focus of their emotional pain to physical pain. They described behaviors including self-beating out of anxiety, banging their heads against the wall in moments of extreme nervousness, and induced vomiting, which is intended to soothe their sense of stress. For example:

“It happens to me when I feel frustrated, or when the pressure in my head gets very big, when things get out of control, or when I feel like I’ve done something that’s out of place, or when I fail, I can’t stand myself in these moments....” (R, 4)

Some of the participants described having an emotional relationship to objects and imparting emotional meanings to the inanimate environment over the human environment. For example:

“I have more connection to objects than people, it... it can be, yes, objects make me feel more confident than people....” (R, 5)

Participants also stated that RRBs help them cope with change, which they consider to be a source of stress and distress. The participants noted their high levels of sensitivity when being exposed to change and described negative emotions such as fear of the changes they experience. For example:

“I need to know where I am, who I am.... I am always afraid that ... that some change will happen, that I won’t be me anymore... how would I think of myself, like, the environment is the thing that determines who I am.” (R, 14)

Some of the participants described the physical feelings that characterize their anxiety:

“I need some basic feeling that I know what’s going on... if I didn’t know the way there I... I’m already crazy in some sense... The feeling is similar to nausea, maybe.” (R, 11)

Some of the participants explained that they have an almost obsessive need to maintain order and organization. They emphasized that order and organization represent something that is permanent, while disorder indicates the existence of change.

4.4. Reason 4: coping with social communication

The participants referred extensively to repetition in the use of the language, stating that these repetitions are manifested when they have difficulties communicating and in social interactions. The participants described a higher sense of self-confidence in their own ability to engage in a conversation when it deals with one of their known areas of interest. For example:

“I feel safe when I'm talking about what I know... I feel that I understand things, and it's like I'm being listened to.” (R, 10)

Another reason that the participants referred to is the high sense of security in their ability to be part of the conversation with people they are familiar with, for example:

“I feel safe in conversation with my mother, my father, my brothers, my family ... and also with people that I see every day.... With them I less need to relax.” (R, 6)

In addition to the use of repetitive subjects in interpersonal communication, the participants described the use of unique concepts that they have developed for themselves to better understand situations that are unclear to them and that result from their difficulties interpreting situations. For example:

“I have a sort of a language, a world of terms that... the way that I interpret things that I don't really understand, whenever I don't understand things, I have to paint them in stronger colors so that I'm able to see them... and I have to give them a very specific definition, very specific characteristics, it isn't always related to reality.” (R, 9)

5. Discussion

The purpose of this study was to learn more about how individuals with ASD perceive and account for their RRBs. Few studies have been based on direct reports by individuals with ASD (Chamak, Bonniau, Jaunay, & Cohen, 2008; Milton, 2014). The current study contributes to a better understanding of the ways in which HFASD perceive their own RRBs. The study indicated four main reasons for the existence of RRBs: enhancing the ability to function; reducing external stimuli and avoiding communication; coping with stress, distress, and excitement; and coping with social communication.

These findings are consistent with studies that have reported an association between RRBs and differences in sensory patterns and between specific sensory profiles and RRBs (Foss-Feig, Heacock, & Cascio, 2012; Gal, Dyck & Passmore, 2009) and provide support for the presence of sensory processing differences and RRBs in people with ASD (Renzo et al., 2017).

The findings also suggest that individuals with HFASD experience difficulties in emotional regulation. This sometimes leads to RRBs, which take on a function of self-regulation in emotionally stressful situations such as the repetitive use of movement and objects as a mechanism for coping with emotional stress. These findings lend weight to studies conducted on individuals with HFASD (Chamak et al., 2008; Jones et al., 2003).

The use of repetitive movements was described by the participants in this study as helpful in maintaining their levels of arousal and concentration while performing a task. The findings are suggestive of the regulating nature of these behaviors, as well as their role in coping with demands.

In the literature, however, RRBs are often perceived as fully engaging the attention of people with ASD, which would explain why they do not have resources available to cope with their social or educational demands, which in turn restricts their involvement in the social fabric of life (Leekam et al., 2011). By contrast, the findings reported here suggest that the perceptions of individuals with HFASD in terms of their recourse to RRBs in the social environment, their needs, and ways to integrate within it differ considerably from the perceptions of individuals without ASD. In the current study, the participants described unique mechanisms for recording and processing information that account for the manifestation of RRBs in a wide range of areas, including sensory regulation, emotional and behavioral regulation, and others. The literature on ASD provides ample evidence for the existence of specific sensory processes (Ben-Sasson et al., 2009), emotional processes (Samson, Huber, & Gross, 2012), and cognitive processes (Turner, 1999).

The findings suggest that abnormal processing mechanisms cause emotional-cognitive-sensory imbalances and an internal sense of chaos, leading to the need for external order and control of the body and the environment. The RRBs are described as constituting a mechanism that helps cope with this internal chaos. The findings here are also supported by homeostasis theory, which suggests that RRBs can be adaptive in coping with the difficulties experienced by people with ASD (Gal, Dyck, & Passmore, 2009). These repetitive patterns of behavior, according to the participants' perceptions, are positive, even though they also have negative implications, and they help them function in daily life. However, they sometimes have negative consequences, such as difficulties in orienting themselves in an unfamiliar space. The results underscore the disparity experienced by the participants between their perception of their RRBs and society's perception of these same behaviors. The findings show that RRBs play a functional role, so that from their point of view, these behaviors are primarily an advantage because they promote their level of functioning. However, when these individuals are in the company of other people, the oddity and strangeness that often characterizes their RRBs provokes negative reactions from those around them, to the extent that it inhibits their functioning and impairs their ability to integrate into society.

Another disparity between the perception of the participants in the study and society's perception, from their perspective, relates to ways of coping with these behaviors, and “the need to get rid of them.” The findings show that RRBs are very important to people with HFASD. However, their own awareness of the negative reactions of people around them, and their realization that these behaviors are not socially acceptable, may prompt them to feel a need to control them. Therefore, reactions from others do not often lead to the extinction of any particular type of RRB but rather to an attempt to transfer one behavior to another, more acceptable type

of behavior or to defer the unacceptable behavior to a time when they are alone, without other people around them.

These findings thus suggest that if the social environment were more accepting of these behaviors and allowed them to be enacted in public, people with HFASD would feel less inclined to spend long periods of time on their own. The findings point to the role of society in promoting better functioning in people with ASD, as has been argued for other social models of disability. This should encourage further research among adults in the ASD population, to expand professional knowledge and provide appropriate treatment solutions that meet their needs.

6. Limitations and recommendations

Any generalization of these findings to other populations should be considered with caution, especially since it is unclear whether the experiences described by adults with HFASD also reflect the experiences and needs of children with ASD, for example, or those of lower-functioning adults with ASD. People with HFASD can present their point of view about their repetitive behaviors, since they understand that they use these types of behaviors and grasp that it is important to understand that the reasons for their repetitive behavior may be very different from those who are not considered HFASD.

Future research should consider conducting a follow-up study that compares perceptions of RRBs among ASD women as compared with men, specifically because researchers such as Hattier, Matson, Tureck, and Horovitz (2011) found a significant main effect for gender, showing that males had a higher frequency of RRBs than females.

The findings suggest that the core driver of RRBs are mechanisms for sensory, emotional, and cognitive regulation that are ineffective but that nevertheless serve as a way of coping in a world that is sometimes experienced as chaotic. The importance of this finding is apparent in light of the prevailing perception in the literature, and in clinical practice, that RRBs inhibit the capacity of people with ASD to function and participate in society, which leads therapists and other professionals to try to prevent these RRBs from occurring. At the educational level, it is important to increase awareness of the social environment to the role of RRBs, to promote greater acceptance of people with HFASD, with their differences.

References

- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Ben-Sasson, A., Hen, L., Fluss, R., Cermak, S. A., Engel-Yeger, B., & Gal, E. (2009). A meta-analysis of sensory modulation symptoms in individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(1), 1–11.
- Berg, B. (2004). *Qualitative research methods for the social sciences*. Boston, MA: Pearson Education Bourdieu, P.
- Burnard, P. (1991). A method of analyzing interview transcripts in qualitative research. *Nurse Education Today*, 11, 461–466.
- Cervantes, P., Matson, L., Williams, L., & Jang, J. (2014). The effect of cognitive skills and autism spectrum disorder on stereotyped behaviors in infants and toddlers. *Research in Autism Spectrum Disorders*, 8, 502–508.
- Creswell, J. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Davidson, J. (2010). 'It cuts both ways': A relational approach to access and accommodation for autism. *Social Science & Medicine*, 70(2), 305–312.
- Faja, S., & Darling, I. (2018). Variation in restricted and repetitive behaviors and interests relates to inhibitory control and shifting in children with autism spectrum disorder. *Autism* (November).
- Foss-Feig, H., Heacock, L., & Cascio, C. (2012). Tactile responsiveness patterns and their association with core features in autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1), 337–344.
- Hattier, M., Matson, L., Tureck, K., & Horovitz, M. (2011). The effects of gender and age on repetitive and/or restricted behaviors and interests in adults with autism spectrum disorders and intellectual disability. *Research in Developmental Disabilities*, 32, 2346–2351.
- Jones, R., Quigley, C., & Huws, J. (2003). First-hand accounts of sensory perceptual experiences in autism: A qualitative analysis. *Journal of Intellectual and Developmental Disability*, 28(2), 112–121.
- Laliberte-Rudman, D., & Moll, S. (2001). In-depth interviewing. In J. V. Cook (Ed.), *Qualitative research in occupational therapy* (pp. 24–57). Albany, NY: Delmar Thomson Learning.
- Langen, M., Kas, H., Staal, G., van Engeland, H., & Durston, S. (2011). The neurobiology of repetitive behavior: Of mice. *Neuroscience and Biobehavioral Reviews*, 35, 356. <https://doi.org/10.1016/j.neubiorev.2010.02.004>.
- Leekam, R., Prior, M. R., & Uljarevic, M. (2011). Restricted and repetitive behaviors in autism spectrum disorders: A review of research in the last decade. *Psychological Bulletin*, 137(4), 562–593.
- Lidstone, J., Uljarevic, M., Sullivan, J., Rodgers, J., McConachie, H., Freeston, M., et al. (2014). Relations among restricted and repetitive behaviors, anxiety and sensory features in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 8(2), 82–92. <https://doi.org/10.1016/j.rasd.2013.10.001>.
- Loftin, L., Odom, L., & Lantz, F. (2008). Social interaction and repetitive motor behaviors. *Journal of Autism and Developmental Disorders*, 38(6), 1124–1135. <https://doi.org/10.1007/s10803-007-0499-5>.
- Lyall, K., Croen, L., Daniels, J., Fallin, M. D., Ladd-Acosta, C., & Lee, B. K. (2017). The changing epidemiology of autism spectrum disorders. *Annual Review Public Health*, 38, 81–102.
- Matson, L., Matheis, M., Burns, O., Esposito, G., Venuti, P., Pisula, E., et al. (2017). Examining cross-cultural differences in autism spectrum disorder: A multinational comparison from Greece, Italy, Japan, Poland, and the United States. *European Psychiatry*, 42, 70–76. <https://doi.org/10.1016/j.eurpsy.2016.10.007>.
- Milton, E. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism: The International Journal of Research and Practice*, 18(7), 794–802.
- Neggers, Y. (2014). Increasing prevalence, changes in diagnostic criteria, and nutritional risk factors for autism spectrum disorders. *International Scholarly Research Notices*, 1–14.
- Prince-Hughes, D. (2002). *Aquamarine blue 5: Personal stories of college students with autism*. Athens: Swallow Press/Ohio University Press.
- Renzo, M., Castelbianco, B., Vanadia, E., Petrillo, M., Racinaro, L., & Rea, M. (2017). Sensory processing and repetitive behaviors in clinical assessment of preschool children with autism spectrum disorder. *Journal of Child and Adolescent Behavior*, 5(2), 2–8.
- Samson, C., Huber, O., & Gross, J. (2012). Emotion regulation in Asperger's syndrome and high-functioning autism. *Emotion*, 12(4), 659–665.
- Shore, M. (2001). *Beyond the wall: Personal experiences with autism and Asperger syndrome*. Shawnee Mission, KS: Autism Asperger Publishing Company.
- Spradley, P. J. (1979). *The ethnographic interview*. London: Holt, Rinehart and Winston.
- Sutcliffe, S., Delahanty, J., Prasad, C., McCauley, L., Han, Q., Jiang, L., et al. (2005). Allelic heterogeneity at the serotonin transporter locus (SLC6A4) confers susceptibility to autism and rigid-compulsive behaviors. *American Journal of Human Genetics*, 77, 265–279. <https://doi.org/10.1086/432648>.
- Thurm, L., Farmer, C., & Shumway, S. (2013). Repetitive behavior and restricted interests in young children with autism: Comparisons with controls and stability over 2 years. *Autism Reacher*, 6, 584–595.
- Turner, M. (1999). Annotation: Repetitive behaviour in autism: A review of psychological research. *Journal of Child Psychology and Psychiatry*, 40(6), 839–849.
- Uljarevic, M., Arnott, B., Carrington, J., Meins, E., Fernyhough, C., McConachie, H., et al. (2017). Supplemental material for development of restricted and repetitive behaviors from 15 to 77 months: Stability of two distinct subtypes? *Developmental Psychology*, 53(10), 1859–1868.
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Canada: Alehouse.
- Williams, D. (2007). *Nobody nowhere: The extraordinary autobiography of an autistic*. London: Doubleday.