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Autistic adults' experience of restricted repetitive behaviours

Collis, E., Gavin, J., Russell, A., & Brosnan, M.

Centre of Applied Autism Research, Department of Psychology, University of Bath

Author Note

Emma Collis <https://orcid.org/0000-0001-9234-6612>

Jeffrey Gavin <https://orcid.org/0000-0002-5580-276X>

Ailsa Russell <https://orcid.org/0000-0002-8443-9381>

Mark Brosnan <https://orcid.org/0000-0002-0683-1492>

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Correspondence concerning this article should be addressed to Emma Collis, University of Bath,
10W Claverton Down, Bath, BA2 7AY. Email: ec883@bath.ac.uk

Abstract

Background: Restricted and Repetitive Behaviours (RRB) are a core characteristic of autism, though little is known about autistic people's lived experience of these phenomena. Research has defined RRB in terms of: 1) a distinction between higher-order and lower-order RRB; as well as 2) a perceived lack of function and 3) a perceived lack of voluntary control.

Method: Twelve autistic adults without intellectual disability were interviewed to elucidate an understanding of these three issues from their lived experience.

Results: Thematic analysis identified four key themes regarding RRB: Self-regulation; positive impacts; negative impacts and suppression. The distinction between higher-order and lower-order RRB was not reflected in the adults' lived experience. In addition to having both positive and negative impacts, the expression of RRB for some behaviours in certain contexts was largely, though not wholly, under voluntary control. Perceived negative evaluations from others can result in strategies to minimise the expression of RRB to observers, although suppressing RRB can be stressful with a cost to the individual.

Conclusions: These findings provide insight into the important functions of RRB and both its positive and negative impacts. It indicates that future research should look to help maximise the positive impacts and minimize the negative, and consider the impact suppression of RRB has on mental health and functioning.

Keywords: Autism, Restrictive Repetitive Behavior, Adult, Camouflaging, Masking, Self-regulation

Highlights

- Self-regulation of attention, physical tension, and emotional discomfort (e.g. anxiety) are key functions of RRB
- RRB may have both positive and negative impacts for the autistic adult depending on the context
- Suppression of RRB is a reaction to perceived negative evaluations of observers
- The psychometric categorization of higher-order and lower-order RRB may not reflect lived experience

Introduction

Autism Spectrum Disorder (ASD) is characterised by qualitative differences in social communication and interaction and a pattern of restricted repetitive behaviours, interests, and activities (RRB; APA, 2013). While RRB are a defining characteristic of ASD (see Bodfish et al., 2000), and may be perceived by parents/ caregivers as challenging in terms of behaviour management (Lecavalier et al., 2006; Ludlow et al., 2012; South et al., 2005), it is estimated that they are the focus of just 10% of autism research (Kasari & Lawton, 2010). RRB have been defined as behaviours which are repeated in an invariant manner, are topographically consistent, and appear functionless to an observer (Turner, 1999; Leekam et al., 2011). The RRB domain encompasses a wide range of behavioural phenomena which have been categorised as 'lower-order' behaviours (e.g. stereotyped motor movements and hyper- or hypo- reactions to sensory stimuli) and 'higher-order' behaviours, thought to reflect repetition at a conceptual level (e.g., an insistence on sameness and circumscribed interests: Turner, 1999; Leekam et al., 2011). Whilst RRB are not exclusive to autistic people, with repetitive movements seen in typical development during infancy, and are seen to persist in other neurodevelopmental and genetic conditions, some types of RRB, particularly 'higher-order' behaviours, are thought to be more prevalent or exclusive to autism and RRB of both orders are seen to persist into adulthood (Leekham et al., 2011). Similarly, higher-order behaviours often encompass interests that are similar to neurotypical populations, though the intensity of those behaviours may be more pronounced in an autistic population (Grove et al., 2018; Cho et al., 2017).

Factor analytic studies provide evidence to support the low and high order categorisation, and point to a lack of association between lower-order and higher-order RRB in both children (Bishop et al., 2006; 2012; Cuccaro et al., 2003; Georgiades et al., 2010; Mooney et al., 2009; Richler et al., 2010; Tao et al., 2016) and adults (Barrett et al., 2015; 2018; Evans et al., 2017; McDermott et al., 2020). Most research has studied RRB in children and young people, finding lower-order behaviours to be more prevalent in younger children and associated with intellectual disability while higher-order behaviours are reported to occur more frequently in older children without intellectual disability (Esbensen et al., 2009; Militerni et al., 2002). Consistent with this, lower-order RRB have been found to decrease with age in adults to a greater degree than higher-order RRB (Barrett et al., 2018; Hwang et al., 2019). Other researchers have found no

evidence of changes in RRB over time (Georgiades et al., 2010; Hattier et al., 2011) and other factor structures have also been proposed (see Berry et al., 2018, for review), such as a four-factor model of: Repetitive motor movements, Insistence on sameness, restricted interests, and sensory sensitivity (Grove et al., 2021). This four factor model draws distinctions between the sensory and motor behaviours ordinarily grouped into low order RRB and the insistence on sameness and restricted interests behaviours typically grouped as high order RRB. These four factors had moderate correlation between them, with six items excluded for significant cross-loading between factors, suggesting that though subtypes of RRB may be psychometrically distinct, they are also related. It remains to be seen whether and to what extent this relation between high and low order or subtypes of RRBs are reflected in lived experience.

While definitions of RRB include an apparent lack of function to an external observer (Turner, 1999; see also Bodfish et al., 2000; Goldman et al. 2009; Seltzer et al. 2003), this does not mean they lack purpose or are meaningless for the autistic individual themselves. Any function of RRB, however, may be overlooked, as the majority of research uses informants (such as parents, see Jaswal, & Akhtar, 2018) and questionnaire-based assessments that focus on aspects such as frequency and severity of the RRB (such as the RBQ-2, Leekham et al., 2007) with less attention paid to context and function. The increasing involvement of verbally able autistic young people and adults with considerable insight into their condition may overcome the limitations of informant reports, allowing us to pose the question, do autistic people perceive their RRB as 'functionless' i.e. lacking in purpose? Indeed, autistic people have previously reported using RRB as a coping mechanism to self-regulate attention, and access sensory and emotional stimulation, to help to manage uncertainty and anxiety, as well as being something that they enjoy (Davidson, 2010; Kapp et al., 2019; Leekham et al., 2011; Joyce et al., 2017; Kuzminskaite et al., 2020; Wigham et al., 2015). As such RRB may be a valuable mechanism for autistic people to improve their ability to function and cope with their environment (Manor-Binyamini & Schreiber-Divon, 2019). Thus, whilst RRB may appear functionless to an observer, these behaviours may serve important and understandable functions at an individual level. These functions are particularly important to consider given that caregivers report finding RRB challenging and as such eliminating RRB is often the target of

treatments such as Applied Behavioral Analysis (Lecavalier, Leone, & Wiltz, 2006; Ludlow, Skelly, & Rohleder, 2012).

What is unknown is the extent to which the functions of RRB are felt to be under the voluntary control of autistic people. Non-autistic observers of RRB often assume that RRB in autism are involuntary (see Jaswal, & Akhtar, 2018). Kapp et al. (2019) suggest that, initially at least, lower-order RRB are involuntary, with autistic participants reporting a lack of awareness of the initiation of lower-order RRB (see also Robledo et al. 2012; Tammet, 2006). It may be that some lower-order RRB can be brought under voluntary control while other behaviours are experienced as involuntary (see Jaswal, & Akhtar, 2018). Further research is required to understand the voluntary control of higher-order RRB (Russell & Brosnan, 2018). One aspect of voluntary control of RRB may relate to suppression. There is evidence that autistic adults suppress other autistic behaviours through *social* masking in order to avoid stigma and allow autistic individuals to appear 'normal' to others (Cage et al., 2018; Hull et al., 2017; 2019; Robledo et al., 2012). Much research on masking has focused on compensatory strategies used by autistic people to conceal *social* differences (Cage et al., 2018; Dean et al., 2017). Whilst previous research has at times included masking of RRB in a social context, masking RRB has not been the specific focus of that research and as such RRB specific data is not extractable (Livingstone & Happe, 2017; Jorgenson et al., 2020). To date, to the authors knowledge, there has been no published research into suppression or concealment of RRB specifically both in a social context or when the individual is alone.

This study explored the lived experience of RRB of verbally able young autistic adults through a two-stage process. In the first stage, each participant completed a self-report questionnaire (RBQ-2A, Barrett et al., 2015) to identify the RRB they experienced at high and low frequency, and severity on an individual basis. This personalised list formed the basis of the second stage of the study, in which participants were interviewed about the RRB they currently engage in or have engaged in in the past. Specifically, this two-stage process aimed to explore the relationship between higher- and lower-order RRB, the function of RRB (if any), and the perceived voluntary control of RRB, including any intent to suppress RRB.

Method

Participants

Participants were 12 autistic adults (5 male, 4 female, and 3 non-binary), aged between 18-23 ($M = 20.58$, $SD = 1.56$). Clinical diagnosis of Asperger Syndrome or Autism Spectrum Disorder had been previously completed following established protocols (ICD10/11: WHO, 2018) and were verbally confirmed for the purposes of the study but not subject to additional validation. One participant had previously received an Applied Behavioural Analysis Home Programme as intervention for their RRB. Participants were recruited through the use of volunteer sampling, posters and a volunteer research database (Centre for Applied Autism Research). Participant demographics information was collected as part of an online questionnaire, details of which can be seen in Table 1.

Table 1: *Demographic Information*

Highest Education Level		<i>n</i> (%)
	GCSEs or equivalent	1 (8.3%)
	A-Levels or equivalent	9 (75%)
	Undergraduate degree	2 (16.7%)
Occupational Status		
	Full-time Employment	1 (8.3%)
	Student	10 (83.3%)
	Unemployed	1 (8.3%)
Diagnosis		
	Asperger Syndrome	7 (58.3%)
	Autism Spectrum Disorder	5 (41.7%)

Note. $N = 12$. % rounded to .1.

Measures

RBQ-2A (Barrett et al., 2015)

The Adult Repetitive Behaviour Questionnaire-2 (RBQ-2A) was completed by participants online. The RBQ-2A measure is an adapted version of the RBQ-2 (Leekam, Nieto, Libby, Wing, & Gould, 2007), which was developed using content of the Repetitive Behaviours Interview (Turner, 1999) and Diagnostic Interview for Social and Communicative Disorders (Leekham, Libby, Wing, Gould, & Taylor, 2002). The RBQ-2A was adapted for use by autistic adults as a self-report measure. The RBQ-2A is a 20-item questionnaire answered on a 3 or 4- point Likert scale whereby autistic adults rate the frequency or severity of a series of both lower-order (Repetitive sensory motor behaviours) and higher-order (insistence on sameness) RRB. The RBQ-2A was scored in line with previous research on the RBQ-2A and RBQ-2 (Barrett et al., 2015; Barrett, Uljarević, Jones, & Leekam, 2018; Leekam et al., 2007; Lidstone et al., 2014). Whilst some RRB measures identify sex differences (see McFayden et al., 2020), the RBQ-2A does not (Barrett et al., 2015; 2018). This measure was used to provide foundation information for an interview and was not subject to further analysis.

Interview Preparation

Responses to the RBQ-2A (Barrett et al., 2015) were reviewed by the first author prior to each participant's interview, with the items of the questionnaire organised according to the reported frequency/severity of the RRB and whether the behaviour was considered a higher-order or lower-order RRB. A behaviour was considered low frequency if a participant reported it as occurring 'never or rarely', 'one or more times daily', or 'of mild or occasional severity'. High frequency behaviours were those which participants reported as occurring '15 or more times daily', '30 or more times daily', 'marked or notable', or 'serious or severe'. Categorisation of higher-order and lower-order behaviours was based upon the two-factor scale of the RBQ-2A, with Insistence on Sameness behaviours categorised as higher-order and Repetitive Sensory Motor Behaviours as lower-order behaviours. Appendix A highlights the responses to the RBQ-2A for the 12 participants. Four lists for each participant were produced to be presented during the interview. The four lists were identified only by number, so participants were not made aware of the

criteria for each list: List 1 (low frequency, lower-order behaviours), List 2 (high frequency, lower-order behaviours), List 3 (low frequency, higher-order behaviours), and List 4 (high frequency, higher-order behaviours).

Interview Procedure

Interviews were audio-recorded and conducted face-to-face in a quiet interview room, which autistic participants adjusted according to their sensory needs. A semi-structured interview schedule based on previous research of RRB experiences (Joyce et al., 2017), with autism specific modifications to the interview style made, including using literal language, and narrow parameter questions to aid recall (Maras et al., 2018a) was used (see Appendix B).

Participants were presented with the four lists based upon their answers to the RBQ-2A at the beginning of the interview and were asked to select a list to talk about first. Participants were then asked what word or words they would use to describe the behaviours on that list. They then chose which individual item on the list they wished to speak about in more detail, and self-generated a recent example of that behaviour that they were willing to talk about. When a participant struggled to choose one behaviour or one occasion of a behaviour, they were encouraged to talk more generally about the behaviour(s) to help generate examples that they could then choose to discuss in more detail.

A visual structure was used to help facilitate the interview by breaking down each example into before, during, and after the behaviour and displaying this in writing (post-it notes) with the aim of reducing memory load commonly reported as an issue in interviews with autistic individuals (Maras et al., 2018b).

The semi-structured interview was piloted on a non-autistic adult prior to the current study being conducted, and all audio recordings were transcribed verbatim for analysis.

The study received full ethical approval from the University of [anonymised] Psychology Research Ethics Committee.

Method of analysis

Data were analysed using reflexive thematic analysis (Clarke et al., 2015; Braun and Clarke, 2019). This analysis was inductive and grounded within a critical realist framework (Sims-Schouten and Riley, 2007; Braun, Tricklebank, & Clarke, 2013), in which participants' discussions of their lived reality of RRB are understood and interpreted within broader socio-cultural contexts and meanings. One such context to reflect on is that of the interviews and the positionality of those conducting the analysis. All interviews and each stage of analysis were conducted by and with an autistic adult (first author), providing an analytic resource in interpreting meaning in the data as an insider. The analysis began with the first author familiarising themselves with the data through multiple readings of transcripts, from which the generation of initial codes was developed. Initial themes were developed to identify and aggregate shared meaning within the data. In order to further explore interpretation and definition of these themes, all of the data pertaining to each code was read by the other three authors, along with the full transcripts, for a discussion and refinement of themes. Whilst all four researchers agreed on the definition and content of the codes, researcher discussion led to a reduction of themes, with codes being regrouped and subsumed as sub-themes of higher level themes as part of the recursive reflexive thematic analytic process. Verbatim extracts are included in the results section to clarify themes and subthemes; these are labelled by participant number.

Results

The responses to the RBQ-2A are reported in Appendix A. The numbers of RRB reported were: 74 lower-order/ lower frequency; 34 lower-order/ higher frequency; 61 higher-order/ lower frequency; and 57 higher-order/ higher frequency.

Through a process of thematic analysis of the interviews regarding these behaviours, four key themes were developed: 1) Self-regulation (of attention, the body and anxiety); 2) Positive impacts (including pleasurable sensations and pleasurable memories and/or impacts); 3) Negative impacts (including functional and self-injurious); and 4) Suppression (including strategies and resistance). These four themes are described below, and their impact upon the study aims reflected on in the Discussion.

Theme 1: Self-regulation

Self-regulation was reported as a key function of RRB used, either automatically or with voluntary control, as a regulatory coping mechanism in three main areas.

Attention was self-regulated through using RRB either to help focus and concentrate, or to provide a distraction. Whilst attempting to work, participants reported finding themselves making low order repetitive movements to improve focus:

Whenever I have to put a lot of thought into something and concentrate on it, I tend to have these repetitive movements because they help me... keep my brain focused while my body is doing something else. (Participant 2)

I knew that this was a show that commanded attention... So for that I got myself a fidget spinner and started playing with that, and it was nice to just spin that in my fingers knowing that I don't have to look at it and I can still watch the telly and what's going on. (Participant 9)

The above extract illustrates how RRB can be used to help focus attention on a task and improve performance. Likewise, RRB were used by some participants as a distraction from their day, depressive thoughts, sensory issues, and to clear their head:

I find most of my repetitive things I do over and over again, they're kind of mini distractions just to kind of, coping mechanisms just to deal with what's happening. (Participant 8)

RRB may serve an important function in preventing autistic people from becoming overwhelmed, allowing them to move their thoughts and attention away from whatever might be causing them distress, and thus allow them to continue to function afterwards. Both high and low order RRB were also used by participants to occupy themselves and their time to stave off boredom:

Kind of bored? Just kind of something I do when I can't think of anything else to do, I'm like "oh well I'll rewatch (video) now". (Participant 1)

Sometimes just fiddle with my watch or like maybe something on my clothes, be it a button or a pocket, just to... pass the time. (Participant 9)

As such some high order RRB may be default activities used by autistic adults when they do not know what else to do, or in the case of lower- order behaviours, when they cannot do anything else to alleviate or prevent boredom. The same RRB were also reported to regulate bodily sensations; in particular, a sense of built-up pressure or 'pent-up energy'. Interestingly, participants spoke of a need to move their body, especially their hands, and that doing nothing was more distracting and disruptive for them:

I just don't like when my hands aren't doing something? Like when I'm walking I have to have my hands in fists in my pockets, just... I just have to do that because otherwise I'm just aware that my hands aren't doing anything. (Participant 5)

For many participants, stillness was reported as being uncomfortable and distracting, and had both a physical and mental dimension that was alleviated by RRB. This type of self-regulation took the form of both high and low order RRB to alleviate stress and anxiety. Specifically, RRB were used as a form of self-regulation as a reaction to both current stress or as a strategic approach to future stress. For example, when in, or following, stressful or anxiety provoking situations, low order RRB were used as a coping mechanism to help manage or alleviate the stress or anxiety:

When I pace around outside while waiting, it makes me feel less anxious and more relaxed.
(Participant 2)

Equally high order RRB were used in anticipation of a stressful or anxiety-provoking situation in order to reduce uncertainty, increase control, and/or reduce future workload and processing:

That week I was very nervous because I was playing water polo and we were going to have to travel to (place name) to play and so I thought "oh I'll make food to take on the coach" and I

ended up thinking “oh I'll make it and then I can have it all week”. I don't really know why, I was just doing it I guess because maybe the week seemed a bit more crazy to me, so it made sense to have all my meals the same. (Participant 10)

Some high order RRB that might initially seem unrelated to self-regulation were linked to low order behaviours and to a self-regulatory function. Indeed, despite high and low order behaviours being asked about in isolation, eleven of the given examples were linked with behaviours of the other order. For example, Participant 12 linked their collection of dice to their comforting sensory elements and to repetitive movements made with them.

I like them because my ones are very heavy and they're mostly very cold so they feel nice and they're kind of textured which is good. (Participant 12)

Similarly, insisting on only wearing the same clothes (high order) was linked with fascination with the feel of different surfaces (low order)- where restricting clothing was linked to an aversion to certain fabrics or labels and as such this restriction was a form of self-regulating sensory experience as well as stress reduction.

I spend ages choosing new clothes because (of) how they wear, I cut all the labels out of my clothes and I often wear the same things over and over again because I like how they feel and then also I don't have to think about what I'm wearing (Participant 10).

As such low and high order behaviours are seen to co-occur and, in some cases, may be intrinsically linked, and even impact the occurrence of the other, indicating that lived experience may not reflect the psychometric categorization of RRB.

Theme 2: Positive impact

One of the perceived functions of RRB is enjoyment. Several participants reported enjoying many of their RRB because of their positive impacts, either in terms of pleasurable sensations or pleasurable memories that their RRB invoked. For some, the sensory stimulation of RRB were described as enjoyable and

comforting. For example, when talking about the low order RRB of swiveling side to side on a swivel chair, Participant 12 described it as:

It's not exactly like euphoric but it's like a lesser version of that? Just a really- just- it just feels nice, it's a nice kind of feeling like in your stomach. (Participant 12)

Likewise, Participant 9 described how they enjoyed the feeling of using their fidget spinner, saying:

I do like a fidget spinner, it's quite, I feel it's quite satisfying just spin that and there's also this thing I discovered early on with them where you just spin them and then you just move your hand and it's quite a nice- I don't know how to describe this but it's quite a nice surreal feeling.
(Participant 9)

Thus, RRB may be used as a sensory seeking behaviour whereby the autistic person receives positive feedback in the form of sensations, and as a result derives enjoyment from those behaviours.

In some cases, enjoyment was also derived from RRB via their associations with happy memories. This was associated predominantly with RRB focused on specific objects such as 'collectables'. For example, a fascination with rocks (low order) and a resulting rock collection (high order) was strongly associated with the memory of obtaining each rock, and thinking a lot about it:

I like the idea that even though a memory is gone, you still have something from that day. So I guess it's kind of a comforting thing? I think too much about it... (Participant 3)

Theme 3: Negative impact

While the experience of RRB was reported to be positive by many participants, they also discussed several drawbacks or negative experiences of their RRB, including both functional or practical drawbacks and mild self-injury resulting from their RRB.

Functional drawbacks included problems with time management, and issues of inflexibility. In some instances, participants felt unable to do a task due to not having the time to do it properly due to high order RRB:

I don't like to be rushed doing it all. And then after showering, you know, like I need like a good 45 minutes to have a shower (laughs) otherwise I'm just like, "There's no point in doing it".

(Participant 3)

Participants also reported losing track of time and becoming absorbed by their high order RRB to the detriment of sleep or other activities:

And I had to do sketches and things and I couldn't just leave it there. And in the end, it got to about 2 in the morning and I was like "Okay, I have to leave it now". But I couldn't-yeah... yeah.

(Participant 3)

Mild self-injury was another clear negative aspect of some RRB that were physically harmful to participants but were not suicidal in nature. Whilst most RRB were perceived beneficial or harmless in themselves, low order RRB of scratching, skin-picking and self-biting were reported by three participants. These behaviours were perceived to be brought on by heightened anxiety, high levels of stress, or even extreme boredom, and participants reported a complicated relationship with these behaviours:

I'd like it to stop because it's, it's getting worse, I guess? It's not as bad as it was before but, you know it's, you know part of me is like oh I like to scratch it, it's a nice relief? But at the same time I was like, my, my arms are like a different colour where I've been scratching them and have bumps all over it right now and it's going to get worse kind of. I'd rather not have it on my arms.

(Participant 5)

Participants also reported feelings of a lack of control over the behaviour, with Participant 11 referring to it as an "addiction", saying that:

I mean I know I shouldn't do it, but I can't resist it's just... and also it's like this white sticking out? I can't help but want to pull it off and sometimes of course red stuff and blood comes out.

(Participant 11)

There was also a strong automatic component to these behaviours and a lack of initial awareness which could lead to feelings of hopelessness when trying to stop:

I guess it never really seemed to stick anyway, like the second I was focusing on something else my hands would just drift back down again. It was sort of feeling like the tide that couldn't be stopped. (Participant 4)

Theme 4: Suppression

Throughout the interviews, participants demonstrated both an awareness of, and concern with, how their RRB might affect or be perceived by others around them. For example, when asked to describe their RRB, Participant 7 described them as "*Annoying, but not for me*" whilst Participant 10 described hiding their RRB because "*I just feel like people will think it's a bit odd, a bit unusual.*"

Self-consciousness and attitudes of others was prevalent throughout interviews. Indeed, a consistent pattern emerged whereby a lack of understanding of RRB, coupled with a negative response from others towards RRB, was recognised by respondents, resulting in a self-consciousness of their RRB, and leading, in some cases, to suppressing or substituting that behaviour.

It maybe comes back to when I was little and when I used to play with my toys by myself in my bedroom as a little boy ... and was making quite loud noises and then my brother in the other room heard me and he was laughing at me... it made me a bit shy and made me feel maybe I'm being a bit silly (Participant 9)

Eight participants spoke of others who either lacked understanding or did not accept their RRB, resulting in being reprimanded, bullied, or even physically restrained for low order RRB.

He has a very physical approach that I really wish he didn't do, where he'd just grab my hands like this (Participant 5)

This negatively impacted them emotionally, making them “*stressed*”, “*embarrassed*”, and “*more bored*”. The negative attitudes of others were reported as impacting their RRB, resulting in a constant self-monitoring of behaviours, complicated by the perception that these behaviours were automatic, and therefore beyond voluntary control.

I was making sure I wasn't doing it again? I kept being like getting the pen out and being like don't do it, he's already told you not to do that? (Participant 5)

This self-policing of their behaviours could either be reactive (i.e., as a response to someone pointing out or criticising the behaviour) or pre-emptive (i.e., based on previous reactions of others), and for some participants constituted a pre-cursor to suppressing their RRB.

I'm scared of them nagging me like not to do it like mum does (Participant 11)

Indeed, although participants were not specifically asked about suppression, this was frequently reported; ten of the twelve participants self-generated at least one example where they were in some way changing or reducing their RRB in response to or as a result of their social environment.

One strategy involved substituting their RRB for a socially acceptable, or less obvious, alternative. There was evidence of autistic adults changing their RRB so that they are more subtle or appropriate for the current social context. For example, Participant 4, in reference to spinning around and around (low order), gave an example where instead of spinning around, they performed a more socially acceptable behaviour in order to still experience a little of the sensory experience of spinning in a way that would not be considered ‘odd’ by others.

Sometimes I'll find minor excuses to do it... normally I'm ahead on the way to the bus stop... and sometimes I'll like spin around and start walking backwards for a bit, and that's partly to show I'm still paying attention even, and like still willing to converse... but part of it is also just because of that motion feeling. (Participant 4)

Participants also gave examples in which they substituted their behaviours based upon the reactions of specific people around them. Participant 5, in response to being reprimanded by their manager for repetitively taking apart a pen, said that *"I didn't really stop, but I didn't take it apart this time, I just had it in my hands"*, thus substituting the established unacceptable behaviour for a more subtle version of fiddling with the pen.

Another strategy used to suppress RRB involved isolating their RRB to specific environments, typically ones in which they were alone, out of sight of others, whose reactions they wished to avoid. Participant 1, for example, stated that they would isolate the behaviour of repetitively throwing their beanie baby cat, saying *"I would usually just do it in the room, in my room, because (laughs), I don't like doing it in front of other people."* Likewise, Participant 9 spoke of how they would isolate their own repetitive behaviours by stopping the RRB the moment even family members came by, and restarting the behaviour once they had left:

On my own. I do get a little bit shy or even embarrassed when someone else is present... one thing I like to do at home is listen to my music when I'm jumping on the trampoline and sometimes when someone walks by, like my mum or my step-dad just walk by... I tend to stop and then let them carry on and then I can carry on sort of thing. (Participant 9)

And mum often worries about me doing that, so I try not to get caught whilst doing that, because it's like an equivalent of picking your nose, you want to do it sometimes but you don't want to get caught. (Participant 11)

The shame surrounding these RRB may indicate that the negative attitudes of others towards RRB have been internalised. This manifested for some as a struggle to even do their RRB in isolation. Participant 5 when talking about their many childhood collections (high order) said:

This is stuff that brought me joy as a child and if I was in a place where I could be unselfconscious and just sort of, completely let go of everything I'm sure I could, almost recapture... I wouldn't necessarily have a problem in an area with no witnesses to just sort of sit

down with them and do the same sort of stuff again, and be like it's still there at the back of my mind. (Participant 3)

Participants also discussed actively suppressing their RRB, using physical or mental restraint to prevent the RRB from occurring. For example, Participant 5 spoke about their repetitive speech, whereby they would feel that they needed to say one of their set phrases or catchphrases to people without understanding why. They talked of how they would reduce or completely suppress the behaviour depending on the reaction of others:

I do it less when people react to it I suppose, but... if someone's reacted really badly to it then I definitely don't say it in front of them. (Participant 5)

As a result of the negative reactions of others then, the participant eliminated the behaviour with those people because they felt "*embarrassed*", despite the fact that they reported it as being "*fun*" to do and said that it "*makes me laugh*". The negative reactions of others was not the only reason reported for suppression though. Participant 10 spoke of how they had previously physically restrained themselves by sitting on their hands, in order to prevent a negative RRB, saying, "*So I used to do it because I'd like bite my nails, but I think also its pressure's quite comforting*". This particular example can be seen as both an example of suppressing and substituting an RRB, as the restraint in this case also gave a positive sensory feeling.

Participants also concealed distress in relation to their RRBs from others. This was particularly prominent with regard to the 'get upset about minor changes to objects' high order RRB. Participant 8 spoke of how they leant a book to a friend, only to watch "*as if in slow motion*" that friend break the spine of the book. Despite being in significant distress about this, they said:

It was like I didn't say anything at the time because... I appreciate it would have been fairly inconsequential for them so.

Therefore, because they knew that the other person would not understand the distress caused by their actions, they suppressed any outward expression of that distress.

Resistance to Suppression

Not engaging in RRB was also reported by participants as being stressful:

(I was) a bit stressed actually because that was how I was amusing myself I guess, like I said I like to have stuff in my hands, doing something, so kind of forcing myself not to be busy with my hands was stressful. (Participant 5)

It's better now but I used to get all the time in school being told to stop fiddling and stuff, when I was already stressed out and it would make me even more stressed out. (Participant 5)

It is important to note, therefore, that the negative reactions of others did not always lead to suppressing the RRB. Some participants reported actively resisting suppression, while others responded by increasing their RRB. For example, Participant 4 spoke about how they were aware that suppressing certain behaviours, such as insisting on doing things a certain way, may have made things easier for them, but at times they resisted doing so:

But yeah, I, there were a few times where I refused to, don't know if assimilate would be the right word, but there were a couple of times where it may have been better for me to blend in, where I decided to sort of stick to my guns. It hasn't always worked out for the best, but you know, at least I can say I've got my convictions. (Participant 2)

In some instances, autistic adults chose not to suppress or even increased the frequency of their RRB in response to the negative reactions of others:

(I) might have done it more because of it (being told off for their RRB). (Participant 6)

Finally, whilst discussing their RRB, participants often became embarrassed or uncomfortable, and described their RRB as being 'weird', 'stupid' and 'ridiculous' amongst other negative terms. This was in the context of a one-on-one interview where participants knew that the interviewer was also autistic.

Discussion & Implications

The aim of the present study was to explore the lived experience of young autistic adults of RRB to elucidate the relationship between higher- and lower-order RRB, the function of RRB, and the perceived voluntary control of RRB (including any intent to suppress RRB). Thematic analysis from 12 interviews resulted in four themes, namely self-regulation, positive impacts, negative impacts and suppression. The three aims of the study will now be discussed with reference to the four themes.

Questionnaire-based studies of RRB have suggested that higher-order (such as insistence on sameness) and lower-order (such as repetitive movements) can be distinguished psychometrically (Barrett et al., 2015; 2018; Bishop et al., 2006; 2012; Cuccaro et al., 2003; Evans et al., 2017; Georgiades et al., 2010; Mooney et al., 2009; McDermott et al., 2020; Richler et al., 2010; Tao et al., 2016). To explore this, participants were invited to reflect upon both higher-order and lower-order RRB. As expected on the basis of previous epidemiological research, lower-order RRB were more likely to be reported to occur at a lower frequency in this sample of autistic adults (Barrett et al., 2018; Hwang et al., 2019). Evidence of both higher-order and lower-order RRB were identified across all four themes, which may indicate that the lived experience of RRB does not reflect the psychometric distinction between these two factors, though future research should look to ask autistic people directly whether this is the case.

RRB were originally defined as seemingly purposeless to an observer (Turner, 1999; see also Bodfish et al., 2000; Goldman et al. 2009; Seltzer et al. 2003), although recent research has suggested RRB may have clear and identifiable functions for autistic individuals (Davidson, 2010; Joyce et al., 2017; Kapp et al., 2019; Kuzminskaite et al., 2020; Leekham et al., 2011; Manor-Binyamini & Schreiber-Divon, 2019; Wigham et al., 2015). Consistent with this literature, self-regulation of attention, physical tension and emotional discomfort (e.g., anxiety), were identified as key functions of RRB by autistic people. There was evidence consistent with the proposal that a relationship between anxiety and RRB may relate to controlling one's environment and reducing uncertainty (Joyce et al., 2017; Rogers et al., 2012). There was evidence that some participants experienced an urge to physically move and expression of RRB fulfilled this need. Whilst this may largely be related to the expression of lower-order RRB such as fidgeting and possibly related to Attention Deficit Hyperactivity Disorder (ADHD) often reported to co-

occur with Autism (e.g. Antshel & Russo, 2019), examples given such as walking in a prescribed way may also indicate the involvement of higher-order RRB, such as routines. Initial evidence from the study suggests that the same RRB may have multiple functions for different individuals or within different contexts. Future research should look to establish whether this is the case or whether specific RRB may be underpinned by specific self-regulatory function/s. Similarly, the regulation of anxiety was related to lower-order (such as pacing) and higher-order (such as having the same lunch everyday) RRB. As above, this may again indicate that the lived experience of RRB does not reflect the psychometric distinction between these two factors.

RRB also had both positive and negative impacts. Positive impacts are consistent with proposals of a self-stimulatory function of RRB, because it is pleasurable and can be associated with positive memories (e.g. Clements et al., 2018). RRB serving to reduce boredom is consistent with a pleasurable experience, or at least removal of a negative experience. These can be lower-order sensory-motor repetition, such as using a fidget-spinner, or higher-order, such as special interests. Self-injurious RRB highlighted that autistic people can also experience negative impacts with their RRB. These negative impacts can be lower-order, such as repeatedly scraping at skin or higher-order, such as following an extended routine even when aware that there is not time to do so. Joosten et al. (2012) report that context is important for the motivation of RRB; specifically within stress-free contexts RRB may be motivated by sensory enhancement, whereas in stressful contexts RRB may be motivated by anxiety reduction. Thus, there is likely a range of perceived positive and negative impacts of RRB which are dependent upon context (see also Gordon et al., 2020). Whether a RRB is positive or negative for the autistic individual and what the function of a behaviour is, may be a more useful way of looking at RRB. This is particularly important in intervention, which should look to minimise negative impacts and self-injury whilst encouraging self-regulatory and positive RRB, rather than attempting to eliminate all RRB.

RRB have both positive and negative impact, and the study also aimed to explore the extent to which RRB were under voluntary control. There was no evidence that these positive and negative impacts were under voluntary control. However, a self-regulatory function did appear to be under voluntary control, especially for the regulation of attention and anxiety. The urge to self-regulate with body movement was

discussed in terms of the drive being out of voluntary control, but the self-regulation of the urge being under voluntary control through selective performance of particular forms of RRB depending on context. Prior research has suggested that the onset of some lower-order RRB may be beyond voluntary control (Kapp et al., 2019; see also Robledo et al. 2012; Tammet, 2006). The present study indicated that RRB can be used pre-emptively to manage upcoming stressful situations in a voluntary manner. Overall, the interviews indicated that the drive for some lower-order and higher-order RRB may be beyond voluntary control but the expression of RRB can be under voluntary control (see Jaswal, & Akhtar, 2018).

A specific example of the voluntary nature of the expression of RRB, were attempts to suppress RRB. Crucially, the suppression of RRB was a reaction to the perceived negative evaluations of observers. Perspective taking of observers has been argued to be a core deficit of autism (Baron-Cohen et al., 1985) and it is therefore of interest that perspective taking appears to inform the motivation to suppress RRB. It may be that RRB are observed to decrease with age in autistic people, if suppression increases in response to a growing awareness/perception of negative evaluations of observers. Such a hypothesis would require a longitudinal study of RRB. The present cross-sectional study of young adults did suggest that lower-order RRB are less frequently self-reported (using the RBQ-2A). Future research could explore whether this category of RRB are suppressed to a greater degree than other RRB or whether there are other explanations. Within early childhood, RRB are also evident in neurotypical children, albeit at a reduced frequency (e.g. Harrop et al., 2014), and studies exploring trajectories of RRB through adulthood in autism would be welcome.

This would be interesting as questions were raised in the present study concerning the definitions of RRB. Clinical assessments of lower order behaviors focus on repetitive sensory movements, such as repetitive use of objects, lining up toys, unusual sensory interests, hand/finger mannerisms, and flicking/twisting fingers. Higher order RRB focus on instance on sameness and special interests (e.g. Turner, 1999). Relationships to behaviours such as 'fidgeting' and 'collecting things' is interesting, as they are experienced as RRB and likened to what might be colloquially referred to as 'a habit' (such as picking your nose). Russell and Brosnan (2018) identify conceptual differences related to habits and RRB, relating to their voluntary nature and function. Indication of RRB having functions and being under

voluntary control in some contexts are consistent with a distinction from habits. Similarly, having the same meal every day was experienced as an RRB as it served to reduce uncertainty within the environment, rather than simply being a time-saving strategy, for example.

A range of strategies for suppression were evidenced. Participants reported actively suppressing the RRB, substituting the RRB for a less obvious RRB, or self-isolating themselves away from others so that they could engage with the RRB unobserved. Suppressing or substituting RRB share potential similarities with strategies identified in the social masking literature, specifically 'camouflaging', which is an attempt to hide autistic characteristics (Cage et al., 2018; Dean et al., 2017; Hull et al., 2017; 2019; Robledo et al., 2012). As the motivation for suppressing RRB is in response to the perceived negative evaluations of others, this may align with an 'assimilation' component of social masking, that is strategies that reflect trying to fit in. However, a 'compensation' component may be less relevant to RRB. Rather a self-isolation component was reported for RRB and this may reflect a fundamental distinction between suppressing RRB and masking social differences. Whilst actively suppressing RRBs entails *not engaging* in certain behaviours, the masking of some social differences requires *actively engaging* in certain behaviours (e.g. forcing oneself to make eye contact). Future research can explore any relationships between suppression of RRB and masking social difficulties. Social masking is associated with poor mental health (Cassidy et al., 2018; 2019) and there was some initial evidence that suppressing RRB is also stressful for autistic people. Possibly as a consequence of this, some participants reported being resistant to suppressing their RRB. RRB can be considered to be an important part of self-expression for autistic people, who may oppose attempts to change or stop these behaviours (Dawson, 2014). Additionally, in suppressing RRB the autistic individual potentially loses the self-regulatory benefits and positive aspects associated with carrying out those RRB. As such, experiences of anxiety, stress, and sensory issues may accumulate over time and so may have a further negative impact on both mental health and functioning. This may in part explain why autistic people experience such high rates of mental health issues and the prevalence of non-suicidal self-injurious RRB (Maddox, Trubanova, & White, 2017), such as those experienced by participants during periods of particularly high stress. As such, an important consideration for future research is to examine the impact RRB suppression has upon mental health and wellbeing for autistic people.

There was a range of limitations in the present study, not least the small sample size. 12 participants for a qualitative study, however, is well within the recommended number (Clarke et al., 2015). All of the participants had been educated to at least GCSE level (assessed at age 16), and most were university students. The academically able nature of the sample limits the generalizability of the findings. In addition, whilst participants verbally confirmed that they had received a formal clinical diagnosis of autism, this was not verified independently. The role of the researcher must be considered with regard to how their identity may have influenced the interviews and analysis of those interviews. The interviewer [first author] herself is autistic, and as such should be better positioned to elicit open and honest experiences of the potentially stigmatising RRB from autistic participants (Jones, Zahl, & Huws, 2001; Stalker, 1998). The researcher's experience of being autistic should also aid in the interpretation of the interviews, however, although every effort was made to remain reflexive and focus on the data of the interview transcripts, it is possible that their own experiences may have been projected onto the experiences of others. Even within this context, it is important to note for future research that participants reported being embarrassed or uncomfortable talking about their RRB. Future research needs to take very precaution is undertaken to ensure autistic participants are appropriately informed and supported about research into lived experience. It is also important to note that informant and observer report may be unable to capture the experience or incidence of RRB given the use of suppression and isolation in masking RRB in autistic adults. As such, future research should consider the importance of self-report in RRB, and how this may impact research into populations who are unable to self-report.

Overall, autistic young adults indicated that the psychometric categorisation of higher-order and lower-order RRB is not reflected in their lived experience. RRB have a range of functions for autistic people including self-regulation as well as both positive and negative impacts. The expression of RRB are largely, though not wholly, under voluntary control and the functions of RRB are largely, though not wholly, beneficial. Perceived negative evaluations from others can result in strategies to minimise the expression of RRB to observers, although suppressing RRB can be stressful.

Implications

The rich and nuanced account provided by the young autistic adults in the present study about their experience of the repetitive behaviours domain of autism points some ways forward in respect of future research. We learn that in contrast to the idea that these are behavioural repertoires with little meaning, there are important reasons why autistic people do what they do. Questions about purpose and context of RRB can be approached from a range of theoretical frameworks including functional analysis, homeostasis, emotional regulation, social comparison and impression management amongst others in order to further our understanding. Most importantly however, and regardless of theoretical orientation, are the questions as to whether the experience of all autistic people including those unable to self-report is captured by these findings, and how people can be supported to manage their RRB in ways which optimise the positive aspects and minimise negative consequences for them.

Conflicts of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper

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Appendix A: RBQ-2A Frequency and Severity by item

RBQ 2-A Item	Frequency			
	Never or Rarely n (%)	≥ 1 per day n (%)	≥ 15 times per day n (%)	≥30 times per day n (%)
Like to arrange Items in rows or patterns?*	4 (33.3)	8 (66.7)	0 (0.0)	0 (0.0)
Repetitively fiddle with items? (e.g spin, twiddle, bang, twist, or flick anything repeatedly?*	1 (8.3)	4 (33.3)	2 (16.7)	5 (41.7)
Spin yourself around and around?*	8 (66.7)	4 (33.3)	0 (0.0)	0 (0.0)
Rock backwards and forwards or side to side, either when sitting or when standing?*	4 (33.3)	3 (25.0)	5 (41.7)	0 (0.0)
Pace or move around repetitively (e.g walk to and fro across a room, or around the same path in the garden?)*	4 (33.3)	6 (50.0)	2 (16.7)	0 (0.0)
Make repetitive hand and/or finger movements? (e.g flap, wave, or flick your hands or fingers repetitively?)*	3 (25.0)	4 (33.3)	2 (16.7)	3 (25.0)
	Severity/Intensity			
	Never/Rarely n(%)	Mild/Occas n(%)	Marked/Notable N(%)	Serious/Severe N (%)
Have a fascination with specific objects? (e.g trains, road signs, or other things?)*	2 (16.7)	5 (41.7)	5 (41.7)	0
Like to look at objects from particular or unusual angles?*	5 (41.7)	4 (33.3)	3 (25.0)	0
Have a special interest in the feel of different surfaces?*	3 (25.0)	2 (16.7)	7 (58.3)	0
Have a special interest in the smell of people or objects?***	4 (33.3)	6 (50.0)	2 (16.7)	0
Have any special objects you like to carry round?***	6 (50.0)	3 (25.0)	3 (25.0)	0
Collect or hoard items of any sort?***	1 (8.3)	3 (25.0)	8 (66.7)	0
Insist on things at home remaining the same? (e.g furniture staying in the same place, things being kept in certain places, or arranged in certain ways?)*	0	3 (25.0)	8 (66.7)	1 (8.35)
Get upset about minor changes to objects? (e.g flecks of dirt on your clothes, minor scratched on objects?)*	2 (16.7)	6 (50.0)	4 (33.3)	0
Insist that aspects of daily routine must remain the same?***	2 (16.7)	4 (33.3)	4 (33.3)	2 (16.7)
Insist on doing things a certain way or re-doing things until they are 'just right'?***	2 (16.7)	4 (33.3)	4 (33.3)	2 (16.7)

Play the same music, game or video, or read the same book repeatedly?*	0	4 (33.3)	7 (58.3)	1 (8.35)
Insist on wearing the same clothes or refuse to wear new clothes**	3 (25.0)	5 (41.7)	4 (33.3)	0
Insist on eating the same foods, or a very small range of foods, at every meal?*	2 (16.7)	4 (33.3)	6 (50.0)	0

Note: * Loaded onto low order factor, ** Loaded onto high order factor

Appendix B: Interview schedule

Semi-structured Interview

Check room okay for sensory needs. Run through PIS, consent, ask okay to record.

Thank you for agreeing to speak with me today. In the questionnaires you filled out previously you were asked about things you might do or want to do over and over again, such as physical movements and routines you may have. I would like to talk with you about some of those things in more detail today. Would that be okay?

Okay, great. We're going to talk about specific occasions of repetitive behaviours in more detail. As we talk we are going to use post-it notes to begin to build up a picture of that occasion on these sheets. The first box is for anything that was happening just before you started..., the second box is for anything that was happening whilst you were doing..., and the third box is for anything that happened just after you stopped... For example, if it took place in a park, we might write the word park and place it here (*demonstrate*). To help us choose a specific example, I made these lists of repetitive behaviours.

Show the four lists of behaviours taken from RBQ-2A answers (List 1=low/low, List 2=high/low, List 3=low/high, List 4=high/high)

These are lists of some repetitive behaviours you may have. Take your time to look over the lists and choose one that you would like to talk about first.

Allow them time to choose a list.

Great, how would you describe this list of items in your own words?

We're going to talk about one of these behaviours in more detail, which one would you most like to talk about?

Confirm their selection with them and clarify that this is something they do often/sometimes do but don't do often depending on the list.

Okay, great. So we're going to talk some more about... Can you tell me about why you chose this question?

Take your time to think of a recent occasion where you were doing...that you're happy to use as an example, and let me know when you have one.

Okay, great. We're going to talk about specific occasions of repetitive behaviours in more detail. As we talk we are going to use post-it notes to begin to build up a picture of that occasion on these sheets. The first box is for anything that was happening just before you started..., the second box is for anything that was happening whilst you were doing..., and the third box is for anything that happened just after you stopped... For example, if it took place in a park, we might write the word park and place it here (demonstrate). Would you like to start out writing and placing post-it notes or shall I? You can change your mind, move post-it notes around, and remove them at any point.

Do you have any questions before we start?

Ask questions to elicit details to build a description of what happened, the environment etc.

- Where? - describe the place, where they were in that place, why they were there, familiar/unfamiliar?
- Sounds, sight, touch, taste, smell
- When?
- Who else, if anyone, was there? Familiar/unfamiliar, close (relationship), like/dislike, where were they, what were they doing,
- What exactly were they doing?

Once a good overall description of the occasion has been reached, start asking questions about thoughts and feelings.

- At what point did you become aware of the behaviour?
- At what point did you first think about the behaviour?

Before

- What were you thinking about beforehand?
- Was this behaviour on your mind beforehand?
- How did you feel before you were...?
- Physical sensations?
- Internal sensations?

During

- How did you feel whilst doing...?
- Did your feelings change while doing...? - If yes, how did your feelings change while doing...?
- Did you want to be doing...? Why?/Why not?
- What were you thinking whilst doing...?

After

- What were you thinking when you stopped?
- What were you thinking after you stopped?
- How were you feeling when you stopped?
- How were you feeling after you stopped?
- Physical sensations?
- Internal sensations?

Repeat for other lists

Please note. Within quotes ... indicates that some wording has been removed