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**“It feels like holding back something you need to say”: Autistic and Non-Autistic Adults accounts
of sensory experiences and stimming**

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Abstract

Background: Restricted repetitive behaviours and sensory sensitivities are core features of autism and have been explored in childhood. However, few studies have examined adult experiences. Autistic adults have begun reframing repetitive behaviours (which often have negative connotations) as “stimming”, and emphasising the benefits of stimming and need for acceptance. Few studies have examined stimming in non-autistic adults. **Method:** An online survey examined sensory and stimming experiences of 340 adults (160 with an autism diagnosis, 139 suspected autistic, 41 non-autistic). Group differences were examined on categorical responses. A thematic analysis was performed on open-text responses. **Results:** Autistic (diagnosed and suspected) individuals reported greater sensory sensitivity and more stimming than non-autistic adults. Stimming is also performed by some non-autistic adults. Thematic analysis produced three themes. 1) Sensory sensitivity had negative physical, emotional and cognitive effects on individuals. 2) Stimming was a self-regulatory mechanism that allowed for positive and negative emotional expression, and cognitive distraction. 3) Social pressure was a reason for suppressing stimming but this had a negative effect on emotions and cognition. **Conclusions:** This study describes the links between sensory sensitivities and stimming behaviours among autistic and non-autistic adults. Autistic adults describe the positive effects of stimming and the negative effect of social pressure to suppress stims, this challenges the prevailing view (largely from studies in childhood) that stimming is a negative behaviour. The views of autistic adults should be incorporated to assure an understanding of associations between sensory sensitivities and stimming, and to understand how stimming may have beneficial effects.

Keywords: Adulthood, autism, repetitive behaviours, sensory sensitivity, stimming, qualitative analysis

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Highlights

Autistic and non-autistic adults described sensory sensitivities and stimming.

Sensory sensitivity had negative physical, emotional and cognitive effects.

Stimming was described as having positive effects and allowing self-regulation.

Social pressure was described as a reason to suppress stims and had negative effects.

Autistic and non-autistic people who stimmed, reported similar experiences.

Introduction

Restricted repetitive behaviours (RRB) are a core diagnostic feature of Autism Spectrum Disorder (ASD; American Psychiatric Association, 2013). These characteristics are classified as stereotyped repetitive behaviours or circumscribed, restricted or specialist interests. RRB criteria also includes hyper and hypo-reactivity to sensory stimuli and unusual interest in the sensory environment. Previous research has suggested that stereotyped behaviours were more common in autistic younger children or individuals with intellectual impairment, whereas specialist interests were associated with being older (adolescents, young adults) or having higher intellectual ability (Leekam et al., 2011). However stereotyped repetitive behaviours are also reported by autistic adults with and without intellectual impairment (South et al., 2005). Many descriptions of stereotyped repetitive behaviours are negative; seen as hindering external engagement through self-stimulation, impacting learning and as behaviours that should be eliminated (Leekam et al., 2011). To date, most research has focused on stereotyped repetitive behaviours in autistic children often using care-giver reports (Harrop et al., 2014; South et al., 2005), with few exploring behaviours in adulthood or using self-report (Kapp et al., 2019). This focus on childhood and care-giver reports may have influenced attitudes to stereotyped repetitive behaviours. In recent years there has been increased advocacy from within the autism community to defend stereotyped repetitive behaviours (Orsini & Smith, 2010). Incorporating the views of autistic adults, self-stimulating repetitive behaviours have begun to be reclaimed and redefined as “stimming” (Bottema-Beutel et al., 2021; Kapp et al., 2019; Kim & Bottema-Beutel, 2019), although this change in definition and attitude is not universal. Stimming may involve repeatedly performing an action (with or without a prop), and include any sensory domain (e.g. touch, movement, smell, sound, vision, etc). Recently stimming has been described as being common in a wide-range of autistic people regardless of ability level, having beneficial effects (reducing the impact of high sensory or emotional stimulation), and there is a growing demand that stimming is acknowledged and accepted (Kapp et al., 2019; Kim & Bottema-Beutel, 2019; Orsini & Smith, 2010). Importantly stimming has been described as a form of self-regulation, which allows individuals to manage overwhelming sensory and environmental stimuli, as well as cognitive and emotional distress (Kapp et al., 2019). Autistic people writing about stimming describe the beneficial experiences of stimming, the often negative reactions of others to stimming, and the importance of reclaiming stimming as positive and part

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of autistic identity (Kim & Bottema-Beutel, 2019). Where possible we will henceforth use the term stimming to describe stereotyped repetitive behaviours, unless other repetitive behaviours are included or descriptions are ambiguous (Bottema-Beutel et al., 2021). Given the ongoing challenge around attitudes to stimming, it is important to understand how these behaviours are experienced by autistic and non-autistic adults and how they interact with sensory sensitivities. This study will use quantitative and qualitative thematic analysis to examine autistic and non-autistic adults' personal experiences of and reasons for stimming, and how stimming interacts with sensory experiences.

Despite stimming being reported as more common in autistic children than adults, few studies have examined whether stimming changes over time. Stimming seems to be stable during preschool years and between childhood and adolescence (Harrop et al., 2014; South et al., 2005). In a study of current and lifetime (retrospective) stimming for young autistic adults, stimming and other repetitive behaviours were frequently reported but were significantly less prevalent currently compared to retrospectively (Chowdhury et al., 2010). For example, approximately 70% autistic adults who had ever shown stimming behaviours (described as complex hand and finger mannerisms by the authors), also showed those behaviours currently (meaning 30% of individuals had stopped stimming). It is worth noting that these studies relied on parental and carer reports of stimming, and one study has described poor correlations between self-report and parent report of stims and other repetitive behaviours for autistic adolescents (Joyce et al., 2017). It is possible that stims may change (either deliberately or spontaneously) over time and be less likely to be identified as stims by others. It is important to include autistic people's own accounts of stimming to understand how they may manifest across the lifespan, as reports suggest that stimming remains common among autistic adults. To our knowledge, two studies have explored stimming and repetitive behaviours in non-autistic adults using self-report questionnaires (Barrett et al., 2015; Schulz & Stevenson, 2019). Non-autistic adults reported lower scores on the Repetitive Behaviour Questionnaire compared to autistic adults, but stimming was still reported as present. To our knowledge no study has explored non-autistic adults' experiences of stimming in detail through interviews or open-ended questions.

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Despite growing evidence that stimming occurs among autistic and non-autistic adults, further understanding is needed. Several studies suggest that stimming and other repetitive behaviours are associated with sensory stimuli and mental health difficulties. Quantitative and qualitative studies suggest that stimming is significantly associated with sensory sensitivity although the relationship is not yet fully understood (Boyd et al., 2009; Kapp et al., 2019; Leekam et al., 2011; Schulz & Stevenson, 2018). Stimming is hypothesised to have a sensory basis, either caused by or as a way of managing inconsistent sensory input (Davidson, 2010; Lawson et al., 2014). An investigation of the relationship between auditory sensitivity and stimming found that autistic adults did not demonstrate high auditory sensitivity, but variability in auditory sensitivity correlated strongly with stimming behaviours (Kargas et al., 2015). Variability in sensory processing may cause errors in sensory perception or sensory overload, leading to stimming (Haigh, 2018). Studies asking autistic adults about their experiences identified stimming as a self-regulatory mechanism when faced with sensory overload, or overwhelming environment, thoughts or emotions (Kapp et al., 2019; Kim & Bottema-Beutel, 2019; Stewart, 2015). These suggestions of stimming as a mechanism for calming oneself, helping to organise thoughts, or dealing with excess energy or anxiety, are also identified in qualitative interviews with autistic adolescents (Joyce et al., 2017). It is important to note that stimming may also be related to positive emotions such as excitement or as a source of pleasure, although they seem to be less commonly described than stims related to negative emotions (Joyce et al., 2017; Kapp et al., 2019; Robertson & Simmons, 2015). Whether this accurately reflects autistic people's experiences or is influenced by researchers focusing on negative effects is not yet clear. Reasons for stimming have not yet been explored among non-autistic adults, however one study found a similar pattern of associations, i.e. a significant correlation between self-reported sensory sensitivity and repetitive behaviours (Schulz & Stevenson, 2019). Whether the reasons for stimming (or not) are the same among autistic and non-autistic adults is not yet clear. Overall, results among autistic people suggest that both sensory sensitivity and anxiety may trigger stims, but also that stimming may modulate sensory input and support coping, stress relief and dealing with anxiety (Joyce et al., 2017; Stewart, 2015).

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Another factor that is identified when autistic adults describe stimming, relates to social stigma. Autistic adults describe stimming as being viewed negatively by others and as not socially acceptable (Kapp et al., 2019; Kim & Bottema-Beutel, 2019). In a study of 100 autistic adults, 72% of people had been told not to stim at some point (Stewart, 2015). Stims were also deemed less socially acceptable with increasing age, with negative judgements being apparent by early adolescence. These factors often lead to stims being suppressed. A related theme was the desire to behave how one wants, to stim without judgment and to be accepted (Kapp et al., 2019; Kim & Bottema-Beutel, 2019). Importantly, understanding and acceptance of stimming (when it occurred) was positive, liberating and reduced anxiety about stimming (Kapp et al., 2019). Given the growing literature on the negative effects of hiding behaviours to fit in or appear more neurotypical, and importance of community acceptance on the mental well-being of autistic people (Cage et al., 2018; Cage & Troxell-Whitman, 2019; Mandy, 2019), autistic adults' experience of stimming may be important to understand outcomes, barriers to acceptance and to plan future research.

So far, investigations into stimming and sensory sensitivities have largely focused on diagnosed autistic people. There is growing awareness that autism may be under-diagnosed in certain populations such as women and older adults (Green et al., 2019; Roestorf et al., 2019; Van Wijngaarden-Cremers et al., 2014). This may be due to changes in diagnostic criteria, differences in presentation, and difficulties being referred (Gould, 2017; Happe & Charlton, 2012; Wise, 2020). Including individuals who suspect they are autistic but have not received a diagnosis in research may allow representation of previously under-researched autistic populations. Also, few studies have examined stimming and sensory sensitivities among non-autistic adults. Both stimming and sensory sensitivities have been shown to be lower in non-autistic compared to autistic adults, but significant association between these variables have been observed (Robertson & Simmons, 2013; Schulz & Stevenson, 2019). Whether autistic and non-autistic adults show the same pattern of associations between stimming and sensory sensitivities is not yet clear.

The aim of this study was to investigate the frequency of stimming and sensory sensitivity in diagnosed autistic, suspected autistic and non-autistic adults. Questions with open text responses were used to

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explore the relationship between stimming and sensory sensitivity, the reasons for stimming, and the effect of stimming, not being able to stim or using substitute stims on individuals in all three groups.

Methods

Procedure

Prior to commencing research, the study was reviewed and ethical approval was granted from the Goldsmiths, University of London Research Ethics Committee. The survey was hosted on Qualtrics, an online questionnaire platform (Qualtrics, Provo, UT, USA; <https://www.qualtrics.com>). Data was collected in May and June 2019. The study was advertised and promoted on social media, and through in-person support groups in the London area and online support groups for autistic individuals. Autistic and non-autistic people were encouraged to participate. The study was introduced as exploring sensory processing, stimming and neurodiversity, and whether stimming helped to manage sensory overload. Individuals interested in participating visited a webpage containing a detailed description of the study, a consent form, General Data Protection Regulation (GDPR) information, and the study questions (see Materials section for full details). All participants gave informed consent prior to participation and all research was carried out per the Declaration of Helsinki and in keeping with General Data Protection Act, 2018. Participants did not receive compensation for participating. The survey was designed to reduce the likelihood that responses were produced by “bots”, by including multiple consent and GDPR questions, open text responses, and branching (if, then) questions. Information on the time to complete the survey and IP addresses were collected and data was checked for evidence of impossible completion times and repeated surveys from the same IP address.

Participants

Four hundred and ninety-one people opened the survey and started to complete the consent and demographic information (data not reported). Of these, 340 people were included in the current analysis, as they answered “yes” to the question “*Do you do any stims*, or repetitive movements? *Stimming normally describes the way people move sometimes in a repetitive manor, for example finger clicking, chewing (pen lids), rocking on a chair or spinning. There are also things often described as visual stims,*

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these may include watching intently at light refraction off water or specs of dust in the air. Audible stims often include whistling, humming, clapping etc." (the question required a Yes/No response). The description of stimming was developed to be broad so as to include any possible stims. It was based on diagnostic criteria, definitions and descriptions of stimming from autistic adults in the literature (American Psychiatric Association, 2013; Kapp et al., 2019; Stewart, 2015). Of these 340 participants, 160 reported having received a diagnosis of ASD (Diagnosed Autistic Group, DA); 139 people had not received an ASD diagnosis but either suspected they were autistic (self-identified) or were currently seeking a diagnosis (henceforth, Suspected Autistic group, SA); and 41 people were not autistic (Non-Autistic group, NA). The proportion of people included in the analysis (by group) compared to the number who completed the consent and demographic information is shown in Table 1. Note, that the proportion of people answering "yes" to the "Do you stim?" question, was significantly lower in the NA compared to the DA and SA groups.

Materials

Consenting participants provided demographic information (age, race, gender) and whether they had a formal diagnosis of autism (DA), if they suspected they were autistic or were currently seeking a diagnosis of autism (SA), or did not have an autism diagnosis (NA), see Table 1. The SA group completed the 14-item Ritvo Autism and Asperger Diagnostic Screen (RAADS-R; Ritvo et al., 2011), to assess whether it was probable that individuals were autistic. All individuals in the SA group scored above the suggested cut-off of 14 (Mean=34.43, SD=5.98, Range=19-42). In order to minimise the time taken to complete the study, DA and NA groups were not asked to complete the RAADS-R. DA individuals provided information about when they had received their diagnosis. Thirty-four individuals (21.3% of DA group) received their diagnosis before 2013 (prior to DSM-V), and 126 (78.8%) received a diagnosis after 2013, according to DSM-V criteria.

All individuals completed several standardised measures of repetitive behaviours and sensory sensitivities (not reported here) and a series of 15 questions generated for this study relating to stimming and sensory processing, relationships between these variables, and the efficacy of substitute stims.

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Questions were generated based on existing literature, observations and conversations with autistic adolescents and adults, and the personal experiences of one of the research team. Questions required yes/no, ratings on 1-7 Likert scale or open text responses, see Table 2 for details. Questions were presented in the order provided in Table 2, if “No” responses were given for questions 3 or 8 then the survey was terminated at that point.

Analysis

Quantitative exploratory questions: Questions with Yes/No responses and responses on Likert scales were analysed for group differences using Chi-square and ANOVA; differences in efficacy of stim type (preferred versus substitute stims) were compared using paired sample t-tests.

Qualitative Analysis: Responses to the seven open-ended questions (see Table 2) were via text box with no maximum response length. Responses were extracted to NVivo 10 for qualitative analysis (QSR International Pty Ltd. Version 10, 2014; <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/>). Within NVivo, responses were read without demographic information, including autism diagnosis category being visible, to reduce rater bias. A thematic analysis was carried out based on the 6-stage framework laid out by Braun and Clarke (2006, 2019): 1) Data familiarisation, 2) Generating initial codes, 3) Searching for themes, 4) Reviewing themes, 5) Defining and naming themes, 6) Producing a report. The researchers took an inductive approach, immersing themselves in the data and developing themes and codes which reflect both surface meaning and latent underpinnings of experiences (Fereday & Muir-Cochrane, 2006; Grogan & Mehan, 2017). Researchers (RC, TE, EB) independently immersed themselves in the data, and met several times to agree initial codes. Using these codes the authors (RC, TE, EB) applied them to the same selection of responses (20 per question). The codes and possible themes present in these 20 responses were discussed in order to clarify codes and identify where codes should be merged (e.g. where two coders had generated a different word to represent the same code). In further meetings individual approach to the analysis was discussed, codes were refined and added where necessary, discrepancies were resolved and codes finalised, possible themes were discussed. Coding for the remaining responses was coded by TE and EB. Coders met regularly to discuss any concerns about consistency or possible new codes. Themes were refined and named. As well as themes, domain

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summary themes which related to specific questions were also observed. Responses to any question could contribute to a theme but they often clustered into domain summary themes (Braun & Clarke, 2019). Themes were re-examined by group, in order to explore whether responses were common across groups or unique within specific groups. Quotations were selected to illustrate themes. The analysis was informed by the team's background in psychology and one of the team's experiences as an autistic person (GN).

Results

Quantitative exploratory questions

Frequency, mean scores and statistical analyses are reported in Table 3. DA and SA groups reported that they found sensory experiences overwhelming more frequently than NA participants. DA and SA groups were also more likely to use stims and repetitive behaviours to manage sensory overload, to feel like they could not stim, or had changed their preferred stims to be socially acceptable (substitute stims). However, there were no differences between the groups in terms of others reactions to stimming. In all three groups approximately 80% of people had been told not to stim. No group differences were observed in how useful preferred and substitute stims were for managing sensory experiences.

A Paired sample t-test examined whether preferred and substitute stims were equally effective in managing sensory experiences. For each group, preferred stims were rated as being more helpful for managing sensory experiences compared to substitute stims.

Most stims described could be classified as repetitive body-centric stims such as rocking or flapping; described by 38% of the DA group, 36% of the SA group, and 11% of the NA group. Further stims included repetitive movement but involved a prop such as a fidget spinner, piece of plastic or phone (described by 10% of DA, 17% of SA and 2% of NA individuals). Although less common stims involving sound, smell and vision were also described. A high proportion of stims were also classified as self-injurious or painful and included picking, biting, and hair pulling. Although no-one described very severe self-injurious stims, painful stims were described by 12% of DA, 21% of SA and 2% of NA people.

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Qualitative Analysis

Participants described their personal experiences of “stimming”, sensory sensitivity and the relationship between these factors. Questions explored when and why people did or did not “stim” and the consequences for the individual. Three domains were interpreted from responses to the open text questions: 1) the effects of sensory sensitivity or sensory overload, 2) stims as a source of self-regulation, and 3) the reasons for and effects of suppressing stims. See Figure 1 for representation of the domains, themes and sub-themes. Although the number of people classified as NA is smaller than the DA and SA groups, all individuals included in this analysis responded “yes” to the question about whether they performed stims or repetitive behaviours. No differences in themes were noted across groups, all groups included responses that could have been used as quotes to reflect the theme.

Domain 1: Effects of Sensory Overload

Participants described the impact of sensory sensitivity and sensory overload as having a wide range of effects. Although fewer people classified as NA reported sensory sensitivities than in the DA and SA groups, for those who experienced sensory sensitivities the resulting impact was similar. Across all three groups participants described three themes. Sensory stimuli caused negative physical sensations (headaches, discomfort, and disorientation), emotional responses (anxiety, panic, etc) and cognitive effects (confusion, difficulties concentrating).

Theme 1a: physical sensations were always described as negative (“... it feels like I have ants crawling under my skin” DA36, female, 40 years old); were often severe (“Everything hurts and ... everything is electric I'm hot ...” DA48, non-binary, 33 years old); and had lasting effects (“I get sensory overload and can be incapacitated for days with severe headache and vomiting” DA78, female, 44 years old).

Theme 1b: negative emotional responses to sensory stimuli such as feeling anxious, angry and frustrated were also commonly described, “It (sensory stimuli) makes me very confused and anxious” DA158, female, 33 years old and “(sensory stimuli) ... causes anxiety until I feel like I'm going to explode” DA130, female, 35 years old.

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Theme 1c: Negative cognitive effects were also described. Participants reported both confusion (*"I can't think nor decide what to do"* DA195, male, 42 years old and *"I am unable to comprehend anything going on around me"* DA158, female, 33 years old) and finding it difficult to concentrate (*"The noise completely consumes me and I cannot focus on anything else"* SA12, female, 43 years old and *"(sensory stimuli) become so distracting that I can't focus on anything else"* SA142, female, 37 years old).

Domain 2: Stims support Self-Regulation

Stims were described as frequently occurring as self-regulatory behaviours in response to sensory stimuli.

Themes describe stims as a way for individuals to regulate both emotional and cognitive functioning.

Theme 2a: describes stims as a way to Express Emotion. This takes the form of both emotional release (*"I think they help me realign the energy in my body better so stuck energy can flow out of me instead of stay in me and cause me pain"* DA145, female, 34 years old and *"Usually to relieve a build-up of feelings before I get overwhelmed - flapping & singing are when I'm excited, finger flicking when anxious"* SA59, female, 42 years old); an expression of inner feelings (*"When I'm overwhelmed or overly happy or excited"* DA198, female, 19 years old); for pleasure (*"It can also be just pleasant"* DA186, female, 50 years old); and to soothe (*"Calming. Feel safe."* SA12, female, 43 years old and *"I find it comforting and relaxing"* SA211, female, 39 years old).

Theme 2b: describes stims as supporting Cognitive Self-Regulation. Specifically stims allowed people to distract themselves from stressors (*"They seem to help my focus move away from the outside sensory issues and allow me to 'centre' myself and my brain"* DA50, non-binary, 45 years old) and aided concentration (*"Helps me to focus and concentrate or to stay calm in busy or noisy places or when having to sit still"* NA33, female, 58 years old).

As reported above self-injurious stims were reported for all groups. Where self-injurious stims occurred they were usually described in terms of biting or scratching (*"My main stim is chewing/biting my nails. I also scratch my fingers on my head through my hair. When I had longer hair I also found it soothing to pull off the split ends of sections of hair"* DA415, female, 32 years old). Participants described self-injurious stims in quite matter of fact language, and not as either something they wished to stop or continue.

Domain 3: Reasons for and Effects of Suppressing Stims.

As seen in the quantitative data, many people ($\approx 75\%$ of DA and SA, and 35% of NA) did not always stim in their preferred manner. This suppression of preferred stims was apparent in the open text responses. Themes reflected the reasons for suppressing stims, changing or substituting stims and the emotional and cognitive effect of both of these behaviours.

Themes 3a: reasons for suppressing stims were primarily social acceptability of behaviour. This was classified in two ways, responses that reflected implicit social pressure and those that reflected explicit learnt behaviours. For example, implicit social pressures were expressed in the need *“to fit in”* and *“to look ‘normal’ ”*, as well as feeling self-conscious in front of others (*“I don't want to draw attention to myself. I don't like people noticing me or looking at me”* SA142, female, 37 years old). For some individuals implicit social pressure was greater in certain settings (*“Social expectation, particularly in a professional environment”* SA84, non-binary, 38 years old). For others social pressures were described as ubiquitous (*“Even in my own space, I feel a constant pressure from the judgement of others and I am unable to break away from social norms”* SA89, female, 24 years old). Individuals also described explicitly learnt reasons to suppress stims. Being told not to stim was common in both home (*“Some of it is due to having family tell me ‘don't do that, you look retarded’¹ and some of it is because it isn't worth explaining and being treated differently afterwards”* DA104, female, 34 years old and *“I got a lot of ‘don't you embarrass me!’ from my mom in particular when I was growing up”* DA186, female, 50 years old) and occupational settings (*“I have been told by my boss to stop/stay still before. I don't want to get in trouble or distract my co-workers or be embarrassed”* SA179, female, 36 years old).

Theme 3b: describes using Substitute Stims rather than preferred stims. These are universally described as being less obvious (*“This is part of why I developed my toe spelling stim - people cannot see it when you are wearing shoes but you know you are doing it and can see it in your mind”* SA129, female, 35 years old) and/or more socially acceptable (*“I have adapted my in meeting stims to pen spinning now ... I generally spin the pen anti clockwise in my right hand ... as soon as I notice anyone watching me, I swap*

¹ We acknowledge that the language used here is offensive and upsetting. We do not condone this language but feel it is important to quote this individual and reflect autistic lived experiences without censor.

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it to my left hand and spin clockwise or do both at the same time ... this is to distract them into marvelling at my amazing ambidexterity rather than thinking I'm a bit odd" SA179, female, 36 years old). However suppressing preferred stims is generally described as effortful (*"It's like when you get a leg cramp, and you know moving that leg would help, but you're not able to, and eventually that's all that's in your head"* DA104, female, 34 years old) and substitute stims as less effective (*"I try to stim in subtle ways that aren't noticeable ... but sometimes that's not enough to diffuse the anxiety and I start to feel more and more anxious"* SA142, female, 37 years old).

Theme 3c: negative emotions associated with suppressing stims were also described. A wide range of negative emotional responses were described when people felt that they could not stim in their preferred manner. Some of these, like embarrassment (*"It makes me feel ashamed of my behaviour and overwhelmed, like I'm about to burst"* NA62, female, 28 years old) and anxiety (*"My anxiety spikes usually to the point I have to flee"* DA92, non-binary, 32 years old) have been alluded to in other sub-themes. Also described is the frustration of having a coping mechanism that one is not able to use (*"... Like having a cold, and having cold medicine next to you but you can't take it because it's not socially acceptable"* SA72, female/non-binary, 25 years old). Other emotional responses reflect the long term effects of social pressure (*"Sad. Anxious. Frustrated. Self-esteem just drops and I turn inward - all the hateful comments of the past flood into my mind. Basically a bit rubbish!"* SA38, female, 48 years old) and feeling rejected or misunderstood (*"I feel like my will is broken, and that I am not wanted for who I am"* SA99, non-binary, 32 years old) and *"Caged, restrained, trapped"* DA153, female, 53 years old).

Theme 3d: describes negative cognitive effects of suppressing stims. In keeping with the description of stims supporting cognitive regulation, suppressing preferred stims is associated with a lack of concentration and confusion (*"I get flustered. I don't concentrate"* and *"... I don't know what to do or how to act"* DA123, female, 34 years old).

Discussion

We explored experiences of sensory sensitivity and its relationship to stimming among diagnosed and suspected autistic and non-autistic adults. Few studies have included suspected autistic and non-autistic adults; therefore this study provides important information about their experiences. Although stimming

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was more common among diagnosed (88%) and suspected (85%) autistic adults, nearly a third (28%) of non-autistic adults reported that they stimated. Stimming was commonly reported in response to sensory overload (86% of DA, 91% of SA, and 52% of NA; more common for autistic than non-autistic adults), in keeping with theories relating to inconsistent sensory input and processing (Davidson, 2010; Lawson et al., 2014). Autistic and non-autistic adults reported similar rates of having been told not to stim, and how useful preferred or substitute stims were for managing sensory experiences. Across all groups, substitute stims were reported as being less effective than preferred stims for managing sensory sensitivities.

Stimming was less common among non-autistic than autistic adults, but there are similarities across all groups when stimming did occur (especially in response to sensory sensitivities). It is unclear why autistic (compared to non-autistic) adults more frequently report feeling unable to stim and change stims to be more socially acceptable. There are few group differences in the types of stims people report, with all groups reporting flicking or fiddling with their fingers, rocking, twisting hair and rubbing or spinning an object. Stims described by the autistic group seem to involve larger movements which therefore may be more obvious. This is highly speculative however, as stims are largely similar, and the reason for this difference in being able to perform preferred stims may be related to other factors (perhaps frequency of stims) that we have not explored.

In keeping with findings in other studies (as well as diagnostic criteria) sensory overload and hypersensitivity were common among autistic adults and formed the basis for Domain 1 (American Psychiatric Association, 2013; Kapp et al., 2019; Robertson & Simmons, 2015). It is worth noting that all examples provided in this survey reflected hypersensitivity (with no reports of hyposensitivity). Unlike some previous studies positive associations with sensory stimuli were infrequently reported. Some of these differences may reflect the specific questions that were asked. Participants in the current study described sensory hypersensitivities as producing a wide range of negative physical, cognitive and emotional effects. Although other studies have described cognitive and emotional effects of sensory stimuli, only one previous study has described similar physical effects associated with sensory sensitivities (Robertson & Simmons, 2013). Participants in Robertson and Simmons (2013) study reported physical discomfort, nausea and pain associated with sensory sensitivities, but did not describe longer

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lasting effects (i.e. effects having a duration of days) as described by individuals in this study. Participants in the current study also reported negative cognitive effects of sensory sensitivity. Previous studies have reported positive sensory experiences as being a beneficial cognitive distractor (Joyce et al., 2017; Smith & Sharp, 2013), and sensory overload has also been associated with “noisy” thoughts (Kapp et al., 2019) which may be similar to the confusion or difficulty concentrating described in this study. The negative emotional impact of sensory stimuli is in keeping with previous descriptions by autistic adults, with anxiety and frustration being common responses to sensory stimuli (Kapp et al., 2019; Robertson & Simmons, 2015; Smith & Sharp, 2013). These results indicate the substantial, negative effects that sensory overload can have on the individual. It is worth noting that while few non-autistic adults reported sensory overload, for those who did the negative reactions were similar to autistic adults. Although non-autistic adults generally reported less severe effects than autistic adults, some non-autistic individuals did report both anxiety and panic attacks. Whether non-autistic adults reporting sensory overload have a sensory processing disorder (which has been associated with childhood and later adult anxiety) or other condition, is not clear (McMahon et al., 2019).

Domain 2 summarises participants' descriptions of stimming as a way to regulate their own emotional and cognitive responses. Often this was in direct response to the sensory overload described in Domain 1 and is in keeping with theoretical accounts of the relationship between stimming and sensory processing (Davidson, 2010; Lawson et al., 2014). Stimming was described as a way to express both positive (excitement) and negative (anxiety) emotions, although different stims were sometimes reported for negative versus positive situations. This is consistent with descriptions of stimming as a way to release emotions and energy and maintain a sense of internal balance (Joyce et al., 2017; Kapp et al., 2019). Stimming was also described as helping to regulate cognitive processes, aiding concentration and distracting from the negative cognitive impact of sensory overload (Davidson, 2010). These findings are in keeping with previous studies where stimming was shown to help individuals to organise their thoughts, and relieve stress (Joyce et al., 2017; Kapp et al., 2019; Smith & Sharp, 2013). The experiences of stimming provided in this study are overwhelmingly positive. Self-injurious stims were reported quite frequently but were not described as severely harmful. Stimming is described in terms of being a coping

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mechanism for both internal and external (environmental) stressors that has a beneficial impact on emotional and cognitive states. This study suggests that in the absence of societal pressures to suppress stims (Domain 3), stimming is beneficial to the individual.

The final domain described by participants reflects the reasons why individuals do not stim the way they want to (preferred stims), and the impact of suppressing stims on the individual. In keeping with a previous study, participants described others negative reactions to stimming (Kapp et al., 2019). Negative responses to stimming were described as being both explicit (being told to stop, negative comments) and implicit (people staring or moving away). These responses lead to preferred stims being suppressed and often replaced with substitute stims. Substitute stims were described explicitly (both in this study and elsewhere) as being selected to be less obvious and more socially acceptable (Kapp et al., 2019; Robertson & Simmons, 2015). However substitute stims were also described as being effortful to maintain and less effective for self-regulation than preferred stims. As has been suggested in other literature particularly relating to camouflaging, the effort of appearing 'normal' may have significant negative effects on both mental health and available cognitive resources for autistic adults (Cage et al., 2018; Livingston et al., 2019). Importantly, people described stims as being suppressed both in public and in private, even when alone. Previous literature describes stimming being suppressed until alone or with trusted others (Kapp et al., 2019). Although we are not aware of other studies describing the social pressure to not stim as continuing even in private, this has been reported with reference to camouflaging ("I even stop myself doing certain tics and things automatically when I'm by myself and that kinda sucks, that I'm not even me on my own", from Hull et al., 2017 pg. 2529). As reported in Kapp et al. (2019) when stimming was accepted by others, individuals describe stimming openly. The social pressure to not stim and suppressing stims may have significant and wide reaching impacts on individuals' mental health. The pressure to change the preferred behaviours (into socially acceptable behaviours) lead to feelings of rejection, shame and sadness, also described by other studies (Kapp et al., 2019; Livingston et al., 2019). Participants also describe both the cognitive effort to suppress stims and the loss of benefits to cognition from performing preferred stims, both leading to a lack of concentration and reducing available cognitive resources. These responses are similar to those reported when autistic people describe the effort and impact of

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camouflaging (Miller et al., 2021). Frustration is a common response when participants describe having a coping strategy (stimming) but being unable to use it due to social pressure and expectations. These results suggest that it is suppression of preferred behaviour and social pressure that has a negative effect on autistic adults rather than stimming per se.

Overall the results suggest that sensory sensitivities are common and associated with stimming; that stimming has positive effects by supporting self-regulation; and that suppressing stims occurs due to social pressure and has negative effects on the individual. These themes were common across diagnosed, suspected and non-autistic groups. Although the number of non-autistic participants endorsing stimming behaviours was lower than in the autistic groups (as a proportion of those who participated in the study as a whole), the same themes were observed across all three groups of participants. Importantly, all groups reported that stimming was positive and beneficial, but that social pressure was a reason to suppress stims. Increasing understanding and acceptance of stims, so that people can stim freely, is likely to have a positive effect on a wide range of individuals. The impact of sensory sensitivities and the benefits of stimming were milder for the non-autistic group overall, but for some non-autistic individuals the negative effects were severe and similar to the autistic groups. This may reflect that inclusion in the analysis was based on whether individuals responded “yes” to a “Do you stim?” question, leading to a selection bias in the non- autistic group. Previous studies have demonstrated both sensory sensitivities and repetitive behaviours in the general population (Barrett et al., 2018; Robertson & Simmons, 2013) but we do not yet understand how these factors relate to one another in non-autistic adult populations. Further work is required to examine the relationship between sensory sensitivities and repetitive behaviours in autistic and non-autistic adults, as well as whether associations follow the same pattern (as suggested here) or are unique in different groups of adults. Whether autistic traits impact the presence of sensory sensitivities, stimming and the associations between these variables is not yet clear.

The results in this study should be considered within the bounds of several limitations. Participants were recruited through promotion in online support groups and social media, were largely female and were all

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cognitively able to complete the survey independently. Although the study includes a large number of adults, it does not fully represent the autistic community. It is important to note that attitudes to stimming were overwhelmingly positive among the adults included in this survey. However stims may not always be positive and may be harmful as when severe self-injurious stims occur. It is important to acknowledge the potential for stims to be physically harmful or have beneficial effects, and that this may vary within an individual over time or in different situations. Participants were asked to disclose their own autism diagnosis, or that they suspected they were autistic or were not autistic. Diagnosis (or lack thereof) was not confirmed although all DA individuals reported when they had received their diagnosis. Only the suspected autism group were asked to complete an autism screening questionnaire (all suspected autistic individuals scored above cut-off on the screening measure). Despite this lack of confirmed diagnosis, there were no differences noted between the diagnosed autistic and suspected autistic groups, suggesting that they shared characteristics. Similarly, the non-autistic group could not be confirmed as not meeting diagnostic criteria for autism or other neurodevelopmental conditions. Although repetitive behaviours do occur among the general population, it is not clear that the non- autistic group are representative (Robertson & Simmons, 2013). It should also be noted that the majority of the participants in this study report either a diagnosis or suspected they were autistic (n = 299 out of 340 people), with only a small number of people identifying as non-autistic (n=41), therefore conclusions relating to non-autistic individuals should be considered with caution. Participants were not asked to identify any comorbid mental or physical health problems, therefore we cannot account for other conditions where sensory sensitivities or repetitive behaviours may occur. It is also worth noting that the thematic analysis was performed based on participants' responses to open text survey questions. Although qualitative analysis is most often performed on interviews and focus groups, thematic analysis can be applied to data such as these and is therefore an appropriate analysis method. The questions may have emphasised both sensory sensitivities and associations between sensory issues and stimming, therefore future studies with less potentially leading questions are needed to replicate the findings reported here.

Implications

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In conclusion, in a large study of autistic and non-autistic adults we identified associations between sensory overload and stimming, describe the beneficial effects of preferred stimming for the individual and the detrimental effects of suppressing stims due to social pressures. These findings support the need for stimming to be acknowledged as having positive effects for autistic and non-autistic adults, and for more work to be done to improve acceptance of stimming. Understanding the negative impact of both suppressing stims and the social pressure to do so, may be an important step in promoting acceptance of stims. This study suggests that for a proportion of non-autistic adults, stimming is also common and helps people to manage their environment. A better understanding of stimming among non-autistic adults is needed. Further work incorporating the views of autistic individuals and non-autistic people who stim is needed to better understand both the benefits and harmful effects of different types of stims, in different situations, and how these effects may change within an individual over time.

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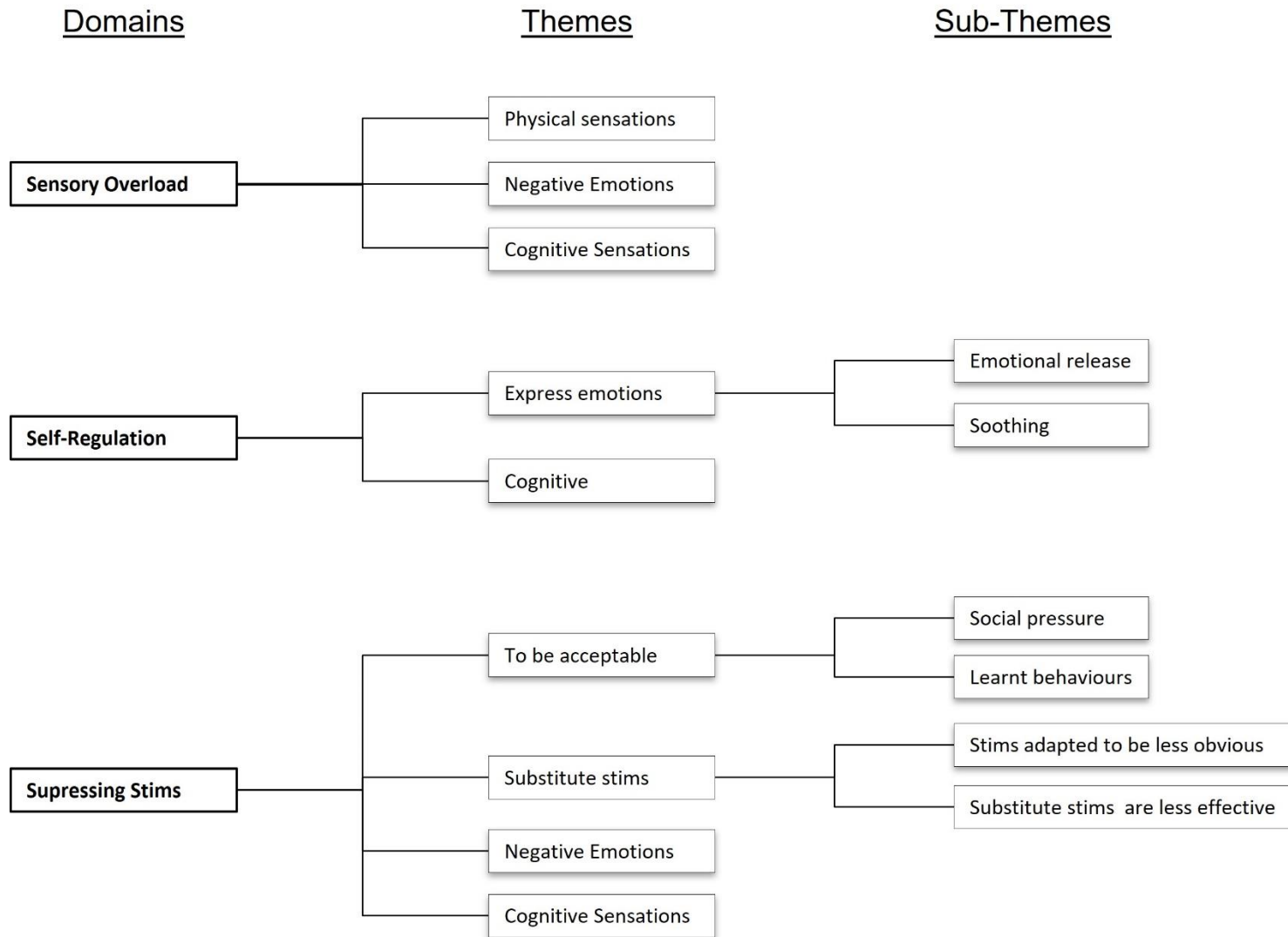
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Figure 1: Domains, Themes and Sub-themes from Thematic Analysis



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Table 1: Sample characteristics by group

	Diagnosed Autistic	Suspected Autistic	Non-Autistic	Statistical Analysis
N	160	139	41	
% included in analysis as proportion of those who completed any of the survey	88%	85%	28%	$\chi^2=190.83,$ $p<.001$
Age: M (SD)	36.59 (9.24)	36.99 (7.93)	35.61 (7.79)	$F=.413, p=.662$
Range	18-60	18-56	21-58	
Gender: Female, Male, Non- Binary/Other, Prefer not to say	129, 12, 18, 1	126, 3, 8, 2	35, 4, 2, 0	$\chi^2=9.47, p=.149$
% Female	80.1%	91.7%	92.4%	
Race: White, Non-white, Prefer not to say	140, 8, 12	122, 12, 5	31, 9, 1	$\chi^2=11.23,$ $p=.004$
% White	94%	91%	77.5%	DA = SA > NA

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Table 2: Exploratory Questions

Question	Response Type
Q1. Do you ever feel your sensory experiences are too much?	Yes//No
Q2. Describe when your sensory experiences are too much	Open Text
Q3. Do you do any stims*, or repetitive movements? (If "No" then no further questions)	Yes//No
Q4. When you feel like you are getting too much input from your senses do you do any stims, or repetitive movements?	Yes//No
Q5. Describe the stims or repetitive movements you do when dealing with sensory overload.	Open Text
Q6. What purpose do these repetitive things or stims serve?	Open Text
Q7. Do you find these stims and/or repetitive movements helpful or useful in managing your sensory experiences?	1-7 scale
Q8. Are there times when you do not stim the way you want to, in response to sensory input? (If "No" then no further questions)	Yes//No
Q9. When do you not stim in the way you want?	Open Text
Q10. Why do you feel like you cannot stim in the way you want to?	Open Text
Q11. Has anyone ever told you not to stim or asked you to stop a repetitive movement you are doing?	Yes//No
Q12. How does it make you feel if you feel like you cannot stim how you want to in response to sensory input?	Open Text
Q13. Do you change preferred stims to be socially acceptable?	Yes//No
Q14. What substitute stims do you do?	Open Text
Q15. How useful are these substitute stims in managing sensory information?	1-7 scale

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Table 3: Frequency and Mean scores for quantitative exploratory questions

	Diagnosed Autistic	Suspected Autistic	Non-Autistic	Statistical Analysis
Question	Frequency of Yes/No response (% Yes)			Chi-square
Q3. Do you do any stims*, or repetitive movements?	160/0 (100%)	139/0 (100%)	41/0 (100%)	
Q1. Do you ever feel your sensory experiences are too much?	147/13 (91.9%)	125/13 (90.6%)	31/10 (75.6%)	$X^2=9.45$ $p=.009$ DA = SA > NA
Q4. When you feel like you are getting too much input from your senses do you do any stims, or repetitive movements?	138/22 (86.3%)	127/12 (91.4%)	21/19 (52.5%)	$X^2=36.39$ $p<.001$ DA = SA > NA
Q8. Are there times when you do not stim the way you want to, in response to sensory input?	116/41 (73.9%)	105/31 (77.2%)	14/26 (35%)	$X^2=28.08$ $p<.001$ DA = SA > NA
Q11. Has anyone ever told you not to stim or asked you to stop a repetitive movement you are doing?	97/18 (84.3%)	80/22 (78.4%)	9/2 (81.8%)	$X^2=1.26$ $p=.533$ DA = SA = NA
Q13. Do you change preferred stims to be socially acceptable?	117/36 (76.5%)	100/34 (74.6%)	15/22 (40.5%)	$X^2=19.94$ $p<.001$ DA = SA > NA
	1-7 Likert Scale, Mean (SD)			ANOVA
Q7. Do you find these stims and/or repetitive movements helpful in managing your sensory experiences?	6.24 (.981)	6.18 (1.03)	6.00 (1.30)	$F=.553$, $p=.576$ DA = SA = NA
Q15. How useful are these substitute stims in managing sensory information?	5.21 (1.40)	5.14 (1.45)	4.92 (1.52)	$F=.467$, $p=.627$ DA = SA = NA
Paired sample t-test examining difference between ratings for preferred and substitute stims (by group)	$t=8.19$, $p<.001$	$t=6.76$, $p<.001$	$t=3.32$, $p=.006$	

*defined in text; note Chi-squared analysis not performed as variable used to select for inclusion. DA = Diagnosed autistic; SA = Suspected autistic; NA = Non-autistic

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