

Beyond self-regulation: Autistic experiences and perceptions of stimming

Neurodiversity
Volume 3: 1–13
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DOI: 10.1177/27546330241311096
journals.sagepub.com/home/ndy



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Abstract

Repetitive, self-stimulatory behaviors (“stimming”) are a hallmark characteristic of autism. Stimming is thought to aid in self-regulation, but autistic perspectives of stimming are underrepresented in the literature. Autistic adults (Study 1 $N = 131$; Study 2 $N = 117$) completed a survey about their autistic identity and their experiences and perceptions of stimming, as well as the functions stimming served. Participants reported stimming to be sometimes positive and sometimes negative, with stimming only being a negative experience when it was self-injurious or stigmatized. Despite frequently being a positive experience, participants purposefully suppressed stimming (“masking”), which was done almost exclusively for extrinsic reasons (e.g. to avoid judgment from others). The majority of participants felt stimming (1) was an important part of their friendship with other autistic people, (2) helped them connect with other autistic people, and (3) that when they saw other autistic people stimming, they could tell what they were feeling. Study 2 found that the degree of connection to the autistic community was the most important predictor of whether stimming served these social-communication functions.

Lay abstract

Stimming, or repetitive self-stimulatory behavior, is commonly seen in autistic people and is believed to help with self-regulation. However, the views of autistic people on stimming are not well represented in academic research. Two studies surveyed autistic adults (131 in Study 1 and 117 in Study 2) about their identity, experiences, and views on stimming, as well as its purposes. Participants reported that stimming could be both positive and negative, with negativity only arising when it caused self-injury or was stigmatized. Although stimming was often a positive experience, many participants intentionally suppressed it to avoid judgment from others. Most participants felt that stimming played a key role in their friendships and connections with other autistic individuals and that it helped them understand each other’s emotions. Study 2 revealed that a strong connection to the autistic community was the most important factor in whether stimming served these social and communicative purposes. Given the potential importance of stimming as social communication within the Autistic community, interventions to enhance social and communication skills in Autistic individuals should consider ways to incorporate stimming. A better understanding of the important roles stimming plays in Autistic people’s lives is beneficial for the well-being of Autistic individuals.

Keywords

Autism, adulthood, participatory research, stimming, social communication

Submission date: 21 June 2024; Acceptance date: 20 November 2024

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Autism is a natural neurodevelopmental variation characterized by differences in sensory processing; speech and language development; and motor control (RADAR, 2022). Consequently, autistic people often have differences in social intuitions and behavioral adaptation. Restricted, repetitive patterns of behavior (RRBs) are one of two major clinical diagnostic criteria for autism spectrum disorder (ASD; American Psychiatric Association, 2013). RRBs are sometimes referred to as “motor stereotypies,” and they encompass a wide continuum from hand/finger flapping to complex whole-body movements (APA, 2013). Historically, autistic communities have been stigmatized by society because of the negative connotations of the terms “repetitive” and “restricted” (e.g. Jaswal & Akhtar, 2019). More recently, however, such behaviors have been described using more value-neutral terms such as “stimming,” or “stims” (e.g. Nolan & McBride, 2015), and we will use these terms throughout this paper.

Various theories to explain the etiology of stimming have been put forward. One theory proposed that stimming and all other autistic behaviors are due to sensory processing abnormalities (Delacato, 1974). Likewise, autism has been described as a syndrome of perceptual inconstancy wherein the motor output of stimming serves to regulate sensory input (Ornitz, 1974; Ornitz & Ritvo, 1968). Several current theories propose that stimming may be a source of familiar and dependable feedback in response to challenges autistic people face in new, unpredictable, and/or overwhelming situations (Lawson et al., 2014; Pellicano & Burr, 2012).

The first descriptions of stimming—dating back to Kanner (1943)—suggested that these behaviors were ways of blocking external stimuli that disrupt the focus of the autistic person and those engaged with them (Lilley, 2017). As described by Jaswal and Akhtar (2019), stimming is often misinterpreted as a sign autistic people are uninterested in social interactions. Recent research on autistic stimming has focused on interventions to reduce or eliminate it (Lanovaz et al., 2013; Lilley, 2017). Behavioral intervention programs such as Applied Behavioral Analysis (ABA) often include modifying, reducing, or outright eliminating stimming as a treatment goal, even if it is not self-injurious (Lanovaz et al., 2013; Lilley, 2017). Such interventions remain prominent despite a lack of efficacy and ethicality of such interventions within the published literature (Jaswal & Akhtar, 2019; Lilley, 2017). Notably, stimming is also present in typically developing, or “neurotypical,” people as well. Common behaviors such as clicking a pen, biting one’s nails, pacing, or repeatedly bouncing one’s leg are indeed repetitive, self-stimulatory behaviors but are rarely considered problematic “symptom” in neurotypical populations.

Interventions to minimize stimming maintain prominence for multiple reasons. This phenomenon is due in part to parents of autistic youth viewing stimming as stigmatizing (Kinnear et al., 2016). Additionally, clinicians point to potential bullying by peers, interference with learning, and

disruption of other students in the classroom as reasons to reduce autistic stimming. Indeed, of the 100 autistic individuals surveyed by Charlton and colleagues (2021), 72% had been told not to stim at some point in their lives and many believe they must adjust their chosen stims to be socially acceptable. In another study, roughly 80% of autistics reported trying to camouflage or hide their stims “often or always” in adulthood; nearly 60% of participants said they also often or always tried to hide stims in childhood (Wiskerke et al., 2018). Many autistic people have discovered techniques to lessen stimming in public in order to be accepted by society. These “solutions” include deliberately suppressing stims by physical constraint or mental self-control, substituting stimming habits like chewing gum or smoking, and engaging in self-isolation (Wiskerke et al., 2018). Autistic scholar-activists have criticized efforts to extinguish stimming as attempts to reduce autistic agency and autonomy (Nolan & McBride, 2015; Richter, 2017).

At the same time, however, there has been growing recognition of the potential beneficial functions of stimming. Autistic adults have described stimming as creating a singular, controllable point of focus in contrast to a broader uncontrollable environment (Kapp et al., 2019). Stimming, then, has been reported to aid in relieving overwhelming sensory input by both drawing attention away from it (Leekam et al., 2011) and quelling any resulting distress or anxiety (Davidson, 2010). Stimming has also been reported to help ease the burden of “noisy” thoughts—including stress about one’s responsibilities, anxiety, and the unknown or uncertainty inherent to daily life (Joyce et al., 2017; Kapp et al., 2019). It is important to note, however, that there is not one uniform experience of stimming among autistic individuals. For example, in a qualitative analysis, Kapp and colleagues (2019) described both autistic individuals who actively chose to stim in preferred ways and others who experienced certain stims unconsciously or as involuntary at their onset.

The stigma around stimming—alongside widespread interventions—has led many autistic people to alter or eliminate their stimming. Such alterations in behavior are often referred to as “masking” by the autistic community. Masking has been qualitatively described as akin to suppressing an itch one has to scratch, or “holding back something you want to say” (Charlton et al., 2021). Autistic self-advocates have acknowledged that suppressing certain stims—such as self-injurious ones—can be beneficial (Lanovaz et al., 2013; Ne’eman, 2010). However, the experience of masking has been reported by autistic adults to be strenuous, debilitating, and sometimes impossible depending on one’s circumstances and ability (Kapp et al., 2019). In fact, the use of masking in social situations to better “fit in” has been reported to be a unique risk factor for suicidality in autistic populations (Bradley et al., 2021; Cassidy et al., 2018). Therefore, having a better understanding of autistic individuals’ stimming experiences is vital to

supporting the positive development and well-being of the autistic community. In particular, it is important to consider the possibility that stimming may hold communicative value and aid in emotional expression, which has rarely been explored in autistic populations.

Participatory research

To better understand stimming from the perspective of autistic individuals, the present study utilized a participatory research approach. In traditional research approaches, questions of interest, methodology decisions, and interpretation of results are driven by academic researchers, often with minimal input from community stakeholders. This approach involves community members only in the role of research participants, although the research is ostensibly conducted for at least some benefit to the community. In contrast, participatory research methods represent an array of approaches that seek to incorporate people's lived experiences into the research about them, including Community-Based Participatory Research (CBPR; e.g. Israel et al., 2001; McDonald, 2017), Participatory Action Research (PAR; Baum et al., 2006; e.g. Kidd & Kral, 2005; MacDonald, 2012), and Civic Science (e.g. Abbott et al., 2014; Garlick & Levine, 2017). Participatory research projects may involve stakeholders outside of academia as community advisors, steering committees, or liaisons to help implement, translate, and disseminate findings to the wider community.

The present study was conducted as part of one such participatory research project: Research on Autism, Driven by Autistic Researchers (RADAR). While RADAR was created by an autistic graduate student, all collaborators have co-ownership of the project and research. In that way, RADAR functions similarly to any other academic partnership. However, collaborators do not necessarily have any prior research experience. RADAR collaborators contributed to all phases of this study: from deciding on the question of interest, to survey development, participant recruitment, and interpretation and dissemination of findings.

Present study

In light of the stark contrasts in opinions surrounding stimming, the primary goal of this study was to better understand autistic adults' perceptions and experiences of stimming as they relate to emotions, social relationships, and communication. As previous research has shown similar patterns of stimming between diagnosed autistic and suspected autistic adults (Charlton et al., 2021), we chose to include participants who either have an autism diagnosis or self-identify as being on the spectrum. In the interest of generalizability of findings, we also elected not to exclude participants based on the presence of

co-occurring conditions, including intellectual disability, so that participants better reflect the diversity of the spectrum. Our primary hypotheses were that (1) stimming is generally experienced positively, (2) masking is experienced less positively and driven by extrinsic motivation, and (3) stimming serves a social-communicative function in the autistic community. Although previous studies have broadly surveyed autistic adults on underlying reasons for stimming (e.g. Bargiela et al., 2016; Charlton et al., 2021), the current study extends this work by considering how stimming functions in autistic social relationships and interacts with other aspects of identity, such as gender, using a mixed-methods design. In this paper, we present the methodology and results of the initial survey (Study 1) and a pre-registered replication (Study 2). Qualitative analysis of follow-up interviews is presented in a separate paper.

Study 1

Methods

This work is exploratory and centers on better understanding the autistic community's lived experience of stimming. To that end, we intentionally did not impose strict criteria as to what qualifies as stimming. Instead, we provided a working definition and examples so that participants understood what we were asking, but it was up to them to decide whether they feel a particular behavior was a stim for them. The definition of stimming provided in the survey instructions is as follows:

“Stimming” is short for self-stimulatory behaviors. Stimming is often a way of getting sensory needs met or regulating sensory experiences. Sometimes people stim without thinking about it, and other times people stim on purpose. Stimming might also be related to the emotions someone is feeling. Sometimes stimming is a need someone can't control, and other times it is just something that feels good to do.

There is no set list of what “counts” as stimming. However, some common autistic stims include rocking, hand flapping, humming, seeking out deep pressure, or playing with fidget toys. Some kinds of stimming are harmful/painful, such as head-banging or pulling out hair. Non-autistic people stim too, but they often stim in different ways, like tapping their pencil or twirling their hair.

Participants. Participants were recruited through social media, online autism groups, outreach to university groups, and flyers. Minimal inclusion criteria were set to enable our sample to be representative of the autistic community more broadly. Participants who (1) were at least 18

Table 1. Study 1 participant demographics.

Characteristic	<i>N</i> = 131 ^a
Age	24.4 (4.83)
Age at diagnosis	11.3 (7.47)
Sex assigned at birth	
Male	48 (36.6%)
Female	81 (61.8%)
Gender identity	
Female	72 (55.0%)
Male	45 (34.4%)
Trans	10 (7.6%)
Non-binary	16 (1.5%)
Other	2 (1.5%)
Race	
Hawaiian/Pacific Islander	3 (2.29%)
Asian	11 (8.40%)
Black	56 (42.7%)
Native	10 (7.63%)
White	57 (43.5%)
Ethnicity	
Hispanic	19 (14.5%)
Non-Hispanic	112 (85.5%)
Highest level of education	
Associate's degree	23 (17.6%)
Bachelor's degree	41 (31.3%)
Graduate or professional Degree	4 (3.05%)
High school/GED	25 (19.1%)
Some college	36 (27.5%)
Employment status	
Unemployed	40 (31.0%)

(continued)

Table 1. Continued.

Characteristic	<i>N</i> = 131 ^a
Disability	5 (3.88%)
Parent	6 (4.65%)
Full-time	20 (15.5%)
Part-time	58 (45.0%)
Diagnosed versus self-identified	
Diagnosed	91 (71.1%)
Self-identified	37 (28.9%)
Support needs	
High	24 (18.3%)
Moderate	60 (45.8%)
Lower	47 (35.9%)

Note: Participants could select multiple options on questions of racial and gender identity, and participants are counted in each category they selected; therefore, proportions do not sum to 100. As very few participants (<5) responded with “prefer not to say,” those responses are not included in the table.

^aMean (*SD*); *n* (%).

years old, (2) resided in the United States, (3) had a professional diagnosis of ASD or self-identified as being on the autism spectrum, and (4) were able to complete the survey in English—with or without assistance—were eligible to take part in the study. After exclusions for incomplete or duplicate responses, the final sample included 131 participants. The average age of participants was 24 years (range 18–48), and the mean age at diagnosis was 11 years ($SD = 7.5$). Most participants reported their gender as female (61.8%), and approximately equal proportions of participants reported their race as White (43.5%) and Black (42.7%). A majority (71.1%) reported receiving a professional diagnosis of autism, while the remaining 28.9% self-identified as being on the spectrum (Table 1).

Procedure. All participants completed screening and e-consent forms in REDCap. After consenting, participants received a link to the Stimming Survey in Qualtrics. As a form of process consent, participants were given multiple opportunities during the Stimming Survey to indicate whether they wanted to continue with the survey or whether they would like to end the survey and no longer be included in the study. At the end of the survey,

participants had the option to provide their email address if they were interested in participating in a follow-up interview. Participants were compensated for completing the survey and interview.

Adults with developmental disabilities may have diminished or fluctuating capacity to consent, but given the nature of an online survey, we could not assess capacity directly. Therefore, participants were asked on the screening form whether they were under guardianship/conservatorship. Participants who responded “unsure” were given follow-up questions about the extent to which they made decisions for themselves. Anyone who indicated they were under guardianship/conservatorship or did not make their own decisions, was required to complete an assent form and have a legally authorized representative give consent on their behalf before receiving access to the Stimming Survey.

Stimming Survey. The Stimming Survey was presented to participants through the online survey system Qualtrics (Supplement 1). The Stimming Survey asked participants about their experiences and perceptions of stimming across a variety of domains. Items included 5-point Likert scale questions, multiple-option questions, and free-text questions. For questions about connection to the autistic community (e.g. “Autism is an important part of my identity”), the role of stimming in social relationships (e.g. “Stimming is an important part of my relationship with other autistic/neurodivergent people.”), and stimming as a form of nonverbal communication (e.g. “When I see other autistic/neurodivergent people stimming, I can usually tell how they are feeling.”), answer options ranged from “strongly disagree” to “strongly agree.”

Participants were also prompted with statements regarding their feelings towards stimming and masking (e.g. “Masking is...”, “Stimming is...”) and responded with answer options ranging from “always a negative experience” to “always a positive experience.” After the Likert scale question about stimming valence, participants were given free text questions asking them to explain why they considered stims to be positive/negative. Following the question on masking valence, participants were asked a free text question on why they mask.

Results

The majority of participants (59%) described stimming as sometimes a positive and sometimes a negative experience; notably, when asked what stims they considered positive/negative, only stims that were self-injurious or stigmatized were described as negative. A third of participants reported stimming as always or usually positive, whereas only a small minority (8%) reported it to be always or usually negative. Participants’ opinions regarding masking were split, with 35% of participants describing it as positive, 30% as negative, and 34% as sometimes positive/negative.

Reasons given for masking were classified as being either intrinsically or extrinsically motivated. More than three-quarters of responses (76%) indicated extrinsic reasons for masking, most frequently to avoid stigma/judgment from others (e.g. “I hate when people feel sorry for me,” “I don’t want to be seen as weak”). Other responses reflected that masking, while initially driven by external expectations and explicit training (e.g. “I had to repress a lot of my autistic traits in childhood for safety and well-being, including stimming (was in ABA as a child)”), had become an internalized, habitual response (e.g. “I had to for so long, to meet expectations. Now it’s hard not to”). Regardless of their opinions on masking, 88% of participants reported masking at least some of the time, and nearly half (49%) mask much or all of the time.

Stimming also appears to play a role in autistic social interactions and relationships. Most participants (56%) agreed that stimming was an important part of their friendships with other autistic people, and nearly two-thirds (63%) agreed that stimming helped them connect with other autistic/neurodivergent people. Additionally, our results support a social-communicative function of stimming, with approximately three-quarters of participants (73%) endorsing the statement, “When I see other autistic/neurodivergent people stimming, I can usually tell what they are feeling.”

Stimming and emotions. Participants report stimming when feeling a range of emotions (Table S1). They were most likely to stim when feeling anxious (50%), frustrated (39%), excited (37%), and angry (33%). Conversely, participants were least likely to stim when feeling sick (11%), tired (15%), focused (17%), in pain (18%), or daydreaming (19%). Common stim-emotion pairings emerged. For example, when excited, many participants said they flap their hands (38.7%) and engage in full-body movements (e.g. jumping/spinning; 33.3%). Pacing when frustrated or anxious (19.4% and 17%, respectively) and picking/scratching skin when bored (19.2%), were also commonly reported. Similarly, 31.6% of participants described biting/chewing their lips, cheeks, or other objects when focused, and 19.3% fidget with objects/toys when bored. No stim was exclusively associated with one particular emotion. Hand flapping, for example, was commonly described as an excited stim, but 25% of participants also reported hand flapping when frustrated.

Discussion

This study builds upon previous literature by showing that stimming is not only common in the autistic population and plays a role in self-regulation, but it also is often experienced positively and considered beneficial to autistic people’s social communication and relationships. The autistic adults in this study painted a nuanced picture of their

experience of stimming; most said there were times when stimming is positive and others when it is negative. This response pattern indicates nuance and complexity in how autistic people think and perceive the world. Very few participants (8%) reported stimming to be generally negative, and only stims that were self-injurious or stigmatized by others were reported to be negative. Overall, most stimming is experienced as positive.

Previous literature and testimonies have indicated masking to be a strenuous and debilitating experience. Indeed, frequent masking/camouflaging is a risk factor for suicidality in autistic adults (Cassidy et al., 2018). Most participants' reasons for masking included either seeking to avoid judgment from others or it being habitual after explicit training to mask earlier in life. Yet, about a third of participants reported masking to be a generally positive experience. It is therefore likely that this question on masking was interpreted differently by different participants; some reported on the process of masking, whereas others reported on the outcome of masking, indicated by the extrinsic reasons provided.

Additionally, most participants affirmed stimming's role as an important component of their friendships and connections with other autistic people, as well as a means of gauging others' emotions. This is especially important to note given the assumption that autism is characterized by lack of interest or impairments in social interactions. In addition to aiding with emotion recognition, stimming also appears to have a link to one's emotional expression. Autistic adults often engage in specific forms of stimming depending on the precipitating emotion. Ekblad and Pfuhl (2017) found that, in comparison to neurotypical people, neurodivergent people more often expressed their internal feelings with particular non-verbal stims. Autistic individuals in that study reported stimming when feeling a variety of emotions. While stimming was most frequently associated with high arousal, negative emotions, other research has found that most autistic adults attest that they do not inherently dislike their stims (Kapp et al., 2019).

At present, there is a paucity of literature regarding the socioemotional effects of autistic stimming. The findings from Study 1 implicated stimming as a potentially important component of autistic social interaction. Further research is needed to replicate these results. Several limitations of Study 1 should be noted, however. We found duplicate survey responses and, in some instances, basic biographical information (e.g. gender, race/ethnicity) provided by participants in follow-up interviews did not match their survey responses. Given the inherent limitations of online data collection (e.g. Teitcher et al., 2015), we implemented additional data quality checks in Study 2 similar to those recommended by Wang and colleagues (2022). Furthermore, we did not include any measure of the degree of autistic traits exhibited by participants. Finally, as Study 1 was exploratory in nature, many

questions were free response, yielding small numbers of respondents offering even the most common stim-emotion pairs. In Study 2, we sought to further explore the link between specific stims and emotions by including multiple-choice survey questions asking participants whether they engaged in specific patterns of stimming drawn from the most common stim-emotion pairs from Study 1.

Study 2

Methods

Participants. Participants were recruited through flyers, online autism groups, and an online participant recruitment platform (Prolific). Participants eligible to participate were (1) 18+ years of age, (2) resided in the United States, (3) had a clinical diagnosis of ASD or self-identified as being on the autism spectrum, (4) and had the ability to complete the survey/interview in English, with or without assistance. After exclusions for incomplete responses, the final sample included 117 participants. The average age of participants was 31 years (range 18–48), and the mean age at diagnosis was 16 years ($SD = 11.5$). Most participants reported their gender as female (57%), and most participants reported their race as White (80%) or Black (15%). A majority (71%) reported receiving a professional diagnosis of autism, while the remaining 29% self-identified as being on the spectrum (Table 2). The mean Autism Quotient (AQ) score of participants (see below) was approximately 39 ($SD = 8$; range = 14–48).

Materials

Autism Quotient (AQ). The AQ is a questionnaire developed by Baron-Cohen et al. (2001) that is designed to assess traits associated with autism across various domains. The AQ is a multiple-choice questionnaire with a 4-point Likert-scale answer format with answers ranging from “Definitely agree” to “Definitely Disagree.” The survey consists of 50 questions, with 10 questions each assessing areas of social skill, attention switching, attention to detail, communication, and imagination (e.g. “I prefer to do things with others rather than on my own,” “I find social situations easy,” “I find it easy to do more than one thing at once”). Scores on the AQ range from 0 to 50, with a higher score indicating more autistic traits. The threshold for distinguishing between those who have clinically significant levels of autistic traits and those who do not is a score of 32 (Baron-Cohen et al., 2001).

Stimming Survey. The Stimming Survey used in Study 2 (Supplement 2) was nearly identical to the one used in Study 1 and covered topics of autistic identity; stimming type, frequency, and general feeling towards stimming; masking frequency, reasons, and general feeling towards masking; relation between stimming and emotions; and

Table 2. Study 2 participant demographics.

Characteristic	N = 117 ^a
Age	31.0 (8.23)
Age at diagnosis	16 (11.47)
Sex assigned at birth	
Male	49 (41.9%)
Female	67 (57.3%)
Intersex	0 (0%)
Gender identity	
Female	55 (47.0%)
Male	46 (39.3%)
Trans	9 (7.69%)
Non-binary	17 (14.5%)
Other	3 (2.56%)
Race	
Hawaiian/Pacific Islander	0 (0%)
Asian	9 (7.69%)
Black	17 (14.5%)
Native	3 (2.56%)
White	94 (80.3%)
Ethnicity	
Hispanic	12 (10.3%)
Non-Hispanic	107 (89.7%)
Highest level of education	
Associate's degree	11 (9.4%)
Bachelor's degree	15 (12.8%)
Graduate or professional degree	19 (16.2%)
High school/GED	34 (29.1%)
Some college	38 (32.5%)

(continued)

Table 2. Continued.

Characteristic	N = 117 ^a
Employment status	
Unemployed	23 (19.7%)
Disability	7 (5.98%)
Parent	5 (4.3%)
Full-time	43 (36.8%)
Part-time	37 (31.6%)
Diagnosed versus self-identified	
Diagnosed	91 (71.1%)
Self-identified	37 (28.9%)
Support needs	
High	5 (4.27%)
Moderate	15 (12.8%)
Lower	97 (82.9%)

Note: Participants could select multiple options on questions of racial and gender identity, and participants are counted in each category they selected; therefore, proportions do not sum to 100. As very few participants (<5) responded with “prefer not to say,” those responses are not included in the table.

^aMean (SD); n (%).

stimming in neurodivergent social interactions and relationships. Item type varied by question, with Likert-scale, multiple option, and free text responses. After the free response section on how they stim when feeling a particular emotion (“When I feel ____, I stim by ____.”), participants were given a set of 23 questions pulled from the most common stim-emotion pairs identified from Study 1. In this section, we presented a stim (e.g. flapping hands) and four response options: a) “I don’t do this,” b) “I do this when [specified emotion],” c) “I do this independent of mood,” and d) “I do this for another reason.” The proportion of participants who selected the second response option was an index of the prevalence of the stim-emotion pair.

Procedure. All study measures were administered via REDCap. Participants completed initial screening and demographics forms to assess their eligibility to participate in the study. Eligible participants received a follow-up invitation to complete the e-consent form, AQ, and the updated

version of the Stimming Survey. As a form of process consent, participants were given multiple opportunities during the Stimming Survey to indicate whether they wanted to continue with the survey or would like to end the survey and no longer be included in the study. As in Study 1, participants who indicated they were under guardianship and/or didn't make decisions for themselves provided assent, while their legally authorized representative gave consent. At the end of the survey, participants had the option to provide their email address if they were interested in participating in a follow-up interview.

Data analysis. In Study 2, we created an indicator variable assessing participants' connection to the autistic community. The four items that composed the indicator variable were (1) "I feel positively about being on the spectrum," (2) "I feel connected to the autistic community," (3) "Autism is an important part of my identity," and (4) "I have friends who are autistic and/or neurodivergent (e.g. ADHD, dyslexic, etc.)." Responses for questions 1–3 were coded from 0 (strongly disagree) to 4 (strongly agree). Question 4 was a yes/no question. Participants could also select an "I'm not sure" option, coded as 0 if participants selected "No," or "I'm not sure" and 1 if participants selected "Yes." Responses were summed such that the indicator variable "connection to the autistic community" score ranged from 0–13.

The analysis plan for Study 2 was pre-registered on OSF. Three social communication questions were the primary focus of the analysis: (1) "Stimming is an important part of my friendship with other autistic/neurodivergent people" (*Friendship*), (2) "Stimming helps me connect with other autistic/neurodivergent people" (*Connect*), and (3) "When I see other autistic/neurodivergent people stimming, I can usually tell what they are feeling" (*Understand*). Each of these are 5-point Likert scale questions with response options of "strongly disagree" (0), "somewhat disagree" (1), "neither agree nor disagree" (2), "somewhat agree" (3), and "strongly agree" (4). For the pre-registered analysis, we recoded data as agree (3–4) or not-agree (0–2) and used binomial logistic regression to test whether endorsement of each statement was related to our focal variable (connection to the autistic community) or other covariates. Each question was analyzed separately using the same procedure.

We identified candidate models using all subsets regression with the following potential predictors: Connection to the autistic community, gender, age, ASD diagnosis status, AQ score, intellectual disability, support needs, and/or the self-reported presence of co-occurring conditions (ADHD vs no ADHD; anxiety vs no anxiety). The best k -predictor models within 4 of the minimum AIC_c value were considered candidate models. Model fit was assessed using leave-one-out cross-validation (LOOCV); the model with

the lowest average cross-validated mean squared error (CV-MSE) was selected as the final model.

To examine whether the validity of stim-emotion pairs varied as a function of particular traits, we first calculated the proportion of participants who reported engaging in the given stim when feeling the specified emotion (response option 2). For each stim-emotion pair that was reported to be valid by at least one-third of participants, we fit a single binary logistic regression model with the same set of potential predictors as above; pairs endorsed by fewer than one-third of participants were not analyzed further. Each stim-emotion pair was treated as an independent hypothesis, and the Benjamini-Hochberg method was used to correct for multiple comparisons within each model.

Results

As in Study 1, the majority of participants (56%) in Study 2 reported stimming to be sometimes positive and sometimes negative. Approximately 38% of participants reported stimming to be a generally positive experience and only 6% reported it as generally negative. Still, most participants (74%) described themselves as stimming throughout most of the day. Participants' opinions on masking were less uniform. Approximately 27% of participants reported masking to be a generally positive experience; 32% as a generally negative experience; and 41% as both. Responses to free-text questions on why participants masked illustrated that approximately 90% did so for extrinsic reasons; 3% did so for purely intrinsic reasons, and 1% provided reasons with aspects of both intrinsic and extrinsic motivation.

Extrinsic reasons for masking fell into one or more categories, including stigmatization ("I feel I need to be seen as normal to be taken seriously or respected," "It's not something my client's parents prefer [sic]"); safety concerns ("people hit me when I was stimmed [sic]," "I don't want to be viewed as weird or a 'crazy n***a'"); and training to mask ("I was taught that these stimming behaviors are not socially acceptable," "I wasn't diagnosed until 50. I had to learn when I was young). Other responses reflected a deliberate cost-benefit analysis in which one weighs the cost of masking against the benefit it gains them in a social context ("It's easier to get what I need out of situations if I control who knows I'm autistic"). Approximately 29% of participants reported 'always' masking; 28% reported masking much of the time; 36% masked sometimes; and only 7% of participants reported never masking.

Social communication and relationships. Stimming again appeared to be involved in participants' social communication and relationships. Approximately 60% of participants stated stimming was an important part of their friendships with other autistic people. Two-thirds of participants

agreed stimming helped them connect with other autistic people; 56% affirmed that when they see others stimming, they can usually tell what they are feeling. Scores on the indicator variable, connection to the autistic community, could range from 0 to 13. The mean value in our sample was 9.0 ($SD = 2.4$; range: 1–13), indicating that most participants felt well-connected to the autistic community.

Model selection: social communication questions. The candidate models for each of the three questions (Friendship, Connect, and Understand) are presented in Table S4. Due to low variability within our sample of both support needs and intellectual disability, we were unable to include those predictors in the model as planned. For the questions about whether stimming is an important part of one's friendships and helps one connect with others, our best fitting model was the 2-predictor model (connection to the autistic community and age; pseudo- $R^2 = 0.45$ and 0.33, respectively). The best fitting model for understanding another's stimming was the one-predictor model with anxiety as the predictor (pseudo- $R^2 = 0.04$). The fitted equations for the best model for each model are:

$$\widehat{\text{Friendship}}_i = 2.41 + 0.59(\text{ASD Comm})_i - 0.06(\text{Age})_i$$

$$\widehat{\text{Connect}}_i = 2.85 + 0.43(\text{ASD Comm})_i - 0.07(\text{Age})_i$$

$$\widehat{\text{Understand}}_i = 0.94 - 0.86(\text{Anxiety})_i$$

Exploratory analysis. No 1-predictor model for the Understand question had an AICc value greater than the minimum AICc + 4, meaning they were all equally plausible. This may be due to the reduced variability in the data that came from recoding responses for binary logistic regression. Therefore, we conducted an exploratory analysis with the same LOOCV process but using the full range of responses (0–4) and treating the data as continuous. Here we used linear regression rather than logistic regression. The candidate models for each of the three questions are presented in Table S5; the variance explained by the adopted models ($R^2 = 0.60, 0.45, 0.05$) was slightly higher than those from the logistic regression analysis. The fitted equations for the best models from this analysis are:

$$\widehat{\text{Friendship}}_i = -0.34 + 0.31(\text{ASD Comm})_i - 0.02(\text{Age})_i + 0.02(\text{AQ})_i + 0.11(\text{ADHD})_i$$

$$\widehat{\text{Connect}}_i = 0.82 + 0.27(\text{ASD Comm})_i - 0.02(\text{Age})_i$$

$$\widehat{\text{Understand}}_i = 1.68 + 0.09(\text{ASD Comm})_i$$

Stimming and emotions. Participants were most likely to stim when feeling high-arousal emotions such as anxiety

(71.4%), excitement (58.1%), and frustration (50.8%; Table S2). However, stimming was also common when participants experienced under-arousal (i.e. boredom, 43.5%). Other emotions yielded considerably lower stimming proportions, such as pain (23.8%), tiredness (21.4%), and sickness (10.1%). For the multiple-choice section on stim-emotion pairs, the proportion of participants who selected the second response option (“I do this when [specified emotion]”) was interpreted as the validity of the stim-emotion pair. The stim-emotion pairs that at least a third of participants endorsed were: singing when happy (48.7%); fidgeting when bored (47%); flapping hands when excited (45.3%); pacing when anxious (45.3%); humming when happy (44.4%); bouncing leg when focused (41.9%); pacing when frustrated (37.6%); and clapping when excited (34.2%; Table S3). Binary logistic regression with the following predictors yielded few significant associations: connection to the autistic community, gender, age, ASD diagnosis status, AQ score, and/or the presence of co-occurring conditions (ADHD vs no ADHD; anxiety vs no anxiety). After correcting for multiple comparisons, only AQ score was a significant predictor of one's likelihood to report singing when happy (−0.11) and pacing when anxious (−0.13).

Discussion

The results of Study 2 largely replicated those of Study 1. Study 2 also included a more stringent screening process to improve data quality and included a measure of autistic traits, the Autism Quotient (AQ). The majority of participants scored above 29, which is 2–3 SDs above the general population mean and aligns with the medium to narrow autism phenotype (Wheelwright et al., 2010). By presenting specific stim-emotion pairs, we were able to assess how common the pairing is in the full sample rather than relying on spontaneous generation of the responses as in Study 1.

Most participants again described stimming as a generally positive experience. While many described stimming as being both a positive and negative experience, only 6% of participants reported it to be generally negative. As in Study 1, stimming was only reported to be a negative experience when it was either self-injurious or stigmatized. Although participants reported frequently stimming (nearly three-quarters of respondents reported stimming throughout most of the day) and positive attitudes towards stimming, the majority of participants nevertheless reported masking, with only 7% of participants indicating that they never masked. It's notable that the proportion of people who said masking was sometimes or usually a positive experience (27%) was less than the proportion who said they masked at least some of the time (36%). This, in combination with the extrinsic reasons given for masking, highlights the external pressures driving this behavior. Even

when autistic adults find stimming to be a positive experience, and masking to be a negative one, they may still suppress their stims due to societal pressures. This indicates social sensitivity and contradicts the notion of autistic individuals as socially oblivious (see Jaswal & Akhtar, 2019).

Connection to the autistic community was the most consistent predictor of the social communication function of stimming. For the questions related to friendship and connection in the logistic regression analysis, and all three questions in the linear regression analysis, each of the best k -predictor models included a connection to the autistic community. Age and gender were also frequently included in the best k -predictor models.

General discussion

Stimming has been historically seen as nonfunctional, although more recently there has been some recognition of its potential importance in self-regulation (e.g. Davidson, 2010; Joyce et al., 2017). Results of the current studies advance our understanding of autistic stimming by revealing its social-communication function and its link to experiencing and expressing a range of emotions. In line with the testimony of various autistic self-advocates (e.g. Bascom, 2012; Orsini & Smith, 2010), participants in these studies indicated that stimming is an important component of their lives, one that is generally positive. Results also challenge suggestions that autistic stimming is involuntary (Yergeau, 2016). Despite stimming being a largely positive experience and the negative mental health outcomes associated with masking—or suppressing stims—many participants in this study indicated they mask frequently. The proportion of people who said masking was sometimes or usually a positive experience was less than the proportion who said they masked at least some of the time. Therefore, participants who may find masking difficult and draining may nevertheless have indicated it was a positive because it let them avoid judgment from others, for example. This possibility will be explored in follow-up interviews with participants. Conversely, although stimming might be intrinsically pleasurable, social stigmatization might make public stimming negative in some instances. Future literature may benefit from surveying autistic adults on their experiences with stimming in both public and private settings to isolate the variable of social pressure. Analysis of participants' free-response answers illustrated that masking was driven almost entirely by the desire to avoid stigmatization and/or punishment. Certain responses indicating both extrinsic and intrinsic reasons for masking appeared to exhibit a deliberate cost-benefit analysis. Extrinsic pressure from others required some participants to either explain their stims to others or mask. This led them to see masking as the “lesser of two evils,” because it took

less effort than continually providing explanations for their stimming (e.g. “*It’s easier than drawing attention to myself, answering questions (often repeats), having to constantly “come out” as autistic is tiring...*”).

The findings from both studies highlight that not only does stimming serve a purpose, but it also has a significant role in autistic social communication and relationships. Given the potential importance of stimming as a social-communication modality within the autistic community, interventions to enhance social and communication skills in autistic individuals should consider working with this modality rather than attempting to eliminate it in favor of more neurotypically normative forms of expression.

Analysis of the indicator variable in Study 2 illustrated that most participants were moderately to highly connected to the autistic community, which may reflect on both the study’s recruitment methods and participants’ perspectives on autism. Many participants were recruited from autistic self-advocacy organizations, service providers, online communities, and word-of-mouth from autistic collaborators involved in the project. By virtue of knowing other autistic people or being at events dedicated to autistic people, these participants would be more connected to the autistic community. Further, the indicator variable assessed participants’ attitudes about autism. Autistic individuals who do not feel positively about being on the spectrum, or do not feel that autism is not an important part of their identity, would be less likely to participate in a study asking personal questions about one’s experiences with autism.

There was still sufficient variability in scores on the indicator variable to examine associations between connection to the autistic community and our outcomes of interest. Although the results may not be fully generalizable to individuals with very low levels of connection, this limitation is inherent to most studies of a particular identity or experience. If one does not feel a trait is an important part of one’s identity, or if one feels very negatively about it, one might be less willing to participate in a study of those experiences—regardless of the sampling strategy employed. Rather than seeing this as a limitation of the study, we note that the high level of connection to the autistic community is interesting in and of itself. These data rebut the prevailing wisdom that autism is characterized by inherent disinterest in social relationships. Indeed, recent research suggests that connection to the autistic community is associated with improved psychological well-being in autistic adults (Cooper et al., 2023) and the social acceptance of stimming enables autistic individuals to demonstrate their unique ways of connecting and empathizing with others (Sterponi & Chen, 2019). Furthermore, our results highlight the need to recognize the value of autistic community and explicitly encourage its development as a connection to the community was associated with social communication outcomes.

Study 2 included a quantitative assessment of autistic characteristics, however... One limitation we note is the use of the Autism Quotient (AQ) in Study 2. We wanted to include a measure of participants' autistic traits and sought other measures that were less disliked by the autistic community, but we were unable to find an available alternative that was suitable for our online self-report survey and provided a reference for interpreting scores. As this is a frequently used measure, the autistic research team decided to include it. Scores on the AQ were not used to determine eligibility, and we feel the score most probably represents the degree to which someone's autism presents stereotypically. Importantly, AQ score was *not* an important predictor in most of our analyses, while our focal predictor—connection to the autistic community—was. We believe these results strengthen the claim that rather than seeing autism as a collection of traits residing inside an individual, we must consider autism in context. Further, that context consists of unique modes of social communication, what one might call culture; in much the same way that the Deaf community has Deaf culture, the autistic community has its own culture.

We note that for the question about one's ability to interpret the emotional content of others' stimming, the variance explained by the adopted model is close to zero. When using information criteria to select a model, adopted models are only the best model given the data and candidate models fitted, allowing the best-performing model relative to the other candidates to still explain very little variation in an absolute sense. Including a direct measure of social ability, emotion recognition, etc., as a predictor would likely have improved variance explained, however, that was not assessed in this study. Using conventional emotion-recognition tasks, for example, the Eyes Task (Baron-Cohen et al., 2001), might not indicate how well one can recognize *autistic* displays of emotions given that they focus on neurotypically normative forms of expression. It is also likely that the wording of the question, "when I see other autistic/neurodivergent people stimming I can usually tell what they are feeling" unintentionally disguised true ability. Given the literal interpretation of questions in this population, we anticipate a portion of participants fixated on the word "usually," providing an answer that was not correlated with actual ability, limiting the ability of the models to explain variation. For example, a participant who can sometimes or even always tell what others are feeling via their stimming might nevertheless have chosen to disagree with the statement because sometimes/always are different from usual.

While the present study had some success in recruiting underrepresented populations in autism research, particularly African-American participants in Study 1, there was less successful recruitment of other racial and ethnic minorities. In addition, few autistic individuals with higher support needs and/or intellectual disability were recruited, especially in Study 2. Although Study 2 included

a more stringent screening process to improve data quality, the limitations inherent to online data collection still apply. As with any online survey, it is difficult to ensure every response is from a unique participant who truly meets the stated inclusion criteria. We chose not to include a phone screening due to the fact that many autistic people find speaking to strangers on the phone challenging and anxiety-provoking and to ensure non- or minimally-speaking autistics could participate in our study. Instead, we separated the eligibility forms from the study measures and reviewed responses across the forms for inconsistencies or responses indicating the individual did not meet inclusion criteria. However, this is admittedly an imperfect process. Finally, we intentionally chose to not require a formal diagnosis or to use co-occurring diagnoses as exclusion criteria. It is possible, then, that some participants would not meet formal DSM-5 criteria for ASD or that responses may be more related to a co-existing condition (e.g. ADHD, anxiety, ID) than autism per se. We feel this imprecision is a worthy tradeoff for a more representative sample and greater generalizability of results. This approach likely facilitated our recruitment of a sample with notable gender identity diversity.


This exploratory study is a step toward reconceptualizing the forms and functions of autistic stimming. More research, both qualitative and quantitative, conducted in collaboration with the autistic community is needed to fully understand the topic. A more thorough recognition of the important roles stimming plays in the lives of autistic people has major implications for the well-being of autistic individuals. Future research utilizing stimming to directly test autistic individuals' ability to recognize the emotional content of others' stims has the potential to challenge the long-held assumption that autistic people are incapable of demonstrating empathy and emotional intelligence. When research sets out to understand how and why autistic people's performance on a particular task differs from neurotypicals' performance without first trying to understand the autistic experience, we are likely to see deficit. Creating truly emic measures that are specifically valid in the autistic population and created in concert with the autistic community is of crucial importance if research is to respond to disability advocates' calls to presume competence. Presuming competence is a matter of dignity and respect for those with disabilities, and it is just as important in research as it is in practice. Much is already known about the areas of difficulty commonly experienced by autistic individuals; presuming competence in our research will enable us to dive deeper into the unique areas of strength, culture, community, and modes of communication in the autistic population as well.


Data availability statement: Data and additional online materials are available at the project's Open Science Framework page (###).

Declaration of conflicting interests: The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding: The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Shared Presence Foundation.

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Supplemental material: Supplemental material for this article is available online.

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