"I'm trying to reach out, I'm trying to find my people" – A mixed-methods investigation of loneliness and loneliness distress in autistic adults

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Abstract

Rates of loneliness are substantially higher among autistic individuals compared to the

non-autistic population. This observation refutes the persistent stereotype that autistic

individuals are not motivated to seek meaningful social relationships. In this two-part,

mixed-methods study, we sought to quantify the level of distress associated with

loneliness in autistic and non-autistic adults and gain qualitative insight into autistic

experiences of loneliness. In Study A, N=209 participants completed questionnaire

ratings of their level of loneliness, associated distress, trait anxiety, depression, and

sensory sensitivity. In Study B, nine autistic adults took part in ten-minute, unstructured

dyadic conversations around the topic of loneliness. We derived a qualitative

understanding of autistic individuals' experience of loneliness, enriched by inductive and

deductive analyses. The autistic group scored significantly higher across all measures and

both groups displayed strong correlations between loneliness and loneliness distress.

The effect of loneliness on anxiety was mediated by increased sensory sensitivity in the

autistic group. Our results oppose the 'social motivation deficit' hypothesis and we

instead frame our findings within the larger context of 'ethical loneliness', concluding that

to enable meaningful and inclusive social interaction, a societal effort is needed to create

spaces that consider the sensory needs of all neurotypes.

Keywords

Loneliness; Autism; Anxiety; Depression; Mixed Methods Research

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Autism Spectrum Disorder (henceforth 'autism') is defined clinically as a neurodevelopmental condition with lifelong difficulties across domains of social communication and interaction, with restricted repetitive patterns of behaviour including hypo- or hyperreactivity to sensory input and information (DSM-5; American Psychiatric Association, 2013). Autism is increasingly framed as an expression of neurodivergence (Beardon, 2017), and conceptualized in terms of differences, rather than deficits (Fletcher-Watson & Happe, 2019). In this work, we make an effort to follow language advice given by the autistic community, for example by using identity-first ('autistic person' instead of 'person with autism') language (Bottema-Beutel et al., 2020).

Autistic people of all ages display higher incidents of physical and mental health problems than non-autistic people (Asztély et al., 2019; Baeza-Velasco et al., 2018; Casanova et al., 2020; Csecs et al., 2022; Hollocks et al., 2019; Lin & Huang, 2019; Rydzewska et al., 2018; Sunwoo et al., 2020). Notably, compared to 10-15% in the general population (Bandelow & Michaelis, 2015), it is estimated that up to 53% of the autistic population meet lifetime criteria for an anxiety disorder (Buck et al., 2014). A recent meta-analysis found that autistic adults are four times more likely to experience clinical depression during their life than non-autistic adults (Hudson et al., 2019).

Loneliness negatively affects physical and mental health, both in neurotypical and neurodivergent individuals (for a recent review, see Quadt et al., 2020). However, rates of loneliness are up to four times higher in autistic than non-autistic individuals (National Autistic Society, 2018), and autistic individuals have a greater vulnerability to the negative physical and psychological consequences of loneliness (Ee et al., 2019). In autistic children and adults, loneliness correlates with increased depression and anxiety (Bauminger & Kasari, 2000; Bauminger et al., 2008; Mazurek, 2014; White & Roberson-

Nay, 2009), is associated with an increase in suicidal thoughts and behaviour (Hedley et al., 2018a), and a greater risk of self-harm (Hedley et al., 2018b).

Sensory processing differences may pose an additional challenge for autistic individuals when seeking meaningful interaction with others. The often-taxing sensory nature of social situations may contribute to increased isolation and thereby exacerbate feelings of depression and anxiety. Differences in sensory processing can manifest both as hyper- (heightened) and hypo- (attenuated) sensory sensitivities (Proff et al., 2021). Sensory sensitivities are overrepresented in the autistic population (Tavassoli et al., 2013) and are associated with increased anxiety (South & Rodgers, 2017), and specific phobias (Muskett et al., 2019). A recent study found that feelings of loneliness, in young autistic adults, mediated the degree to which sensory avoidance predicted levels of anxiety (Syu & Lin, 2018). In other words, loneliness explained why feelings of anxiety were increased by the need to avoid distressing sensory experiences, highlighting an important contribution of sensory processing to the negative effects of loneliness on mental health.

The relationship between loneliness and poor mental health has come more into focus over the last decade, yet the stereotype persists that autistic people are disinterested in meaningful social interactions. Indeed, a deficit in motivation to engage in the social world was hypothesized to be the cause of 'impairments' in communication and 'disrupted interest' in social engagement (Chevallier et al., 2012). This theory is largely at odds with reports from the autistic community of a longing for improved social connection (Causton-Theoharis et al., 2009), and has been criticized on this basis (Jaswal & Akhtar, 2019). A discrepancy in mutual understanding between autistic and non-autistic individuals, rather than an autistic deficit in social motivation, offers a more valid framework for appraising communication difficulties and associated feelings of

loneliness (Milton & Bracher, 2013; Milton et al., 2018; Milton, 2012; Williams et al., 2021).

Loneliness is often conceptualized as the actual or perceived absence of meaningful social connection (Cacioppo et al., 2015; Weiss, 1973), but it is now acknowledged that the size of an individual's social network does not equal the satisfaction with social relationships. In this manner, emotional loneliness (the perceived lack of meaningful social connection) is often distinguished from social loneliness (i.e., social isolation). This distinction is reflected in some psychometric measurement tools, like the Social and Emotional Loneliness Scale for Adults (SELSA; DiTommaso & Spinner, 1993), or the De Jong Gierveld Loneliness Scale (de Jong Gierveld & Tilburg, 2006; de Jong Gierveld & Van Tilburg, 1999). These instruments are considered multidimensional, as they measure more than one dimension of loneliness. In contrast, the UCLA Loneliness Scale (Russell, 1996) is unidimensional, focusing on feelings of loneliness in direct relation to the perceived adequacy and feelings about social relationships (Valtorta et al., 2016).

All three of these prevalent loneliness measures touch on the negative affect and distress associated loneliness through items such as "I have an unmet need for a close romantic relationship" (SELSA), "I miss having people around" (De Jong Gierveld Loneliness Scale), or "How often do you feel that your relationships with others are not meaningful?" (UCLA Loneliness Scale). However, we believe that such measures still do not fully capture the important distinction between chosen solitude and distress caused by loneliness. While potential distress is implied in these questionnaires, there is no explicit measure that assesses whether, and to what degree, loneliness is associated with distress.

To overcome this shortcoming, in Study A, we modified the UCLA Loneliness Scale and added the question "How much does this upset you?" after each original item. This enabled us not only to arrive at an explicit measure of loneliness distress, but also to assess quantitatively the stereotype of 'chosen solitude without distress' attributable to diminished social motivation in autistic adults. In this first study, autistic and non-autistic participants completed the modified UCLA Loneliness Scale, in addition to measures of anxiety, depression, and sensory sensitivity. Based on previous research, we hypothesized that autistic participants would display higher scores on all these measures than non-autistic participants, and that loneliness and distress would be highly correlated in both groups. Given research indicating a relationship between social avoidance, sensory sensitivity and feelings of loneliness (Syu & Lin, 2018), we expected to find a positive relationship between these variables in our cohort. In study B, we undertook a qualitative analysis of the experience of loneliness as described in a subpanel of autistic individuals.

Method

The first, quantitative case-control study (Study A) was a sub-study of the ADIE clinical trial (Quadt et al., 2021) and includes data collected pre-intervention at the baseline assessment only. The second, qualitative study (Study B) was a sub-study of the 'Talking Together': the linguistic ethnographic community engagement project (Williams, 2020b; Williams et al., 2021) based in an interpretivist paradigm. All data was collected before the COVID-19 pandemic.

Participants

Study A involved 109 participants with a formal diagnosis of autism and 100 non-autistic controls. All participants were fluent English speakers. Participants were excluded if they had a history of past head injury or organic brain disorders, moderate to

severe intellectual impairment, epilepsy or psychotic experiences. Autistic participants were recruited from the Sussex Partnership NHS Foundation Trust Neurodevelopmental Service, advertisements placed on social media, leaflets and posters, local support groups, and through clinicians. Non-autistic participants were recruited from staff and students of the University of Sussex and from members of the local community. Participants were matched by gender, age, and level of education for the original study. However, only a subset also filled out relevant self-report measures for this study, and participants for this study were not matched.

In Study B, eight core autistic adult participants (3 male, 5 female) were invited to participate in three short naturalistic conversations (each lasting approximately ten minutes) around the topic of loneliness with: a) a familiar and self-chosen conversation partner; b) an autistic stranger; and c) a non-autistic stranger. The ninth autistic participant included in the analysis attended as the familiar conversation partner of one of the core participants. Autistic participants were recruited through *Assert Brighton and Hove* – a local autism support group for autistic adults – and the non-familiar non-autistic conversation partners were recruited from the University of Brighton. Sampling and data saturation were determined by the primary study (Williams et al., 2021) of which this study was a sub-study. All participants for both studies provided written informed consent with all procedures.

Materials and Procedure

Study A was approved by the NHS Research Ethics Committee and the Brighton and Sussex Medical School Research Governance and Ethics Committee and was conducted with the sponsorship of Sussex Partnership NHS Foundation Trust (SPFT). All participants attended a session at the University of Sussex, or a local SPFT site if autistic participants were unable to travel to University of Sussex. Participants were also given

the opportunity to complete self-report measures at home via the online platform Qualtrics to allow for individual preferences.

Study B was given ethical approval by the Tier II Arts and Humanities Ethics Panel at the University of Brighton. Participants attended the *Assert* premises in the centre of Brighton and held their conversations in a small, familiar meeting room. Participants were provided with two general prompt questions (see Supplementary Material) for each conversation, designed to elicit personal experiences of loneliness and thoughts about loneliness in Brighton and Hove. Conversations were recorded digitally and professionally transcribed, with participants allocated pseudonyms (indicated by an asterisk).

Self-report measures

In Study A, all participants provided demographic information about their age, gender assigned at birth, gender identification, and level of education (see Table 1). They then completed a series of self-report measures either at their study visit or at home via the online platform Qualtrics if they preferred to fill out questionnaires in their own time. Questionnaires included Spielberger State-Trait Anxiety Inventory (STAI; Spielberger, 2010), Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001), Autism Quotient (AQ; Baron-Cohen et al., 2001), Glasgow Sensory Questionnaire (GSQ; Robertson & Simmons, 2013), and UCLA Loneliness Scale (UCLA LS; Russell, 1996) with added items. Specifically, each loneliness question from the UCLA Loneliness Scale was followed by a dedicated question to assess distress, i.e. "How much does this upset you?" in order to calculate a parallel 'loneliness distress' score (see Supplementary Material, pp 2-5). For UCLA LS, two sub-scores (total score of original questions and total score of distress-items) were computed.

Data analysis

SPSS Version 26 was used for data analysis. In Study A, group differences in age and questionnaire scores were determined using independent samples t-tests for continuous measures and Chi-square tests for categorical variables. Where significant (*p*<.050) group differences were found, between-group differences in loneliness, loneliness distress, affective, and sensory measures were assessed using one-way ANCOVAs with added covariates to control for age and level of education. Bivariate Pearson's correlations were performed to assess relationships between variables. The differential relationship between variables in autistics versus non-autistics was determined by computing Fisher's r to z transformation, subsequently comparing z scores and analysing for statistical significance (Lenhard & Lenhard, 2014). Using SPSS PROCESS (Hayes, 2012), a mediation analysis was conducted to estimate a potential explanatory effect of sensory sensitivity on the relationship between anxiety and loneliness, with loneliness as the outcome and trait anxiety as the predictor variable, and bootstrapped (n=5000) confidence intervals.

In Study B, qualitative coding and analysis of the transcribed conversations was undertaken in the NVivo data analysis programme (QSR International Pty Ltd, 2020): software designed to assist in the management of qualitative datasets. Qualitative thematic analysis is an iterative and reflexive process (Braun & Clarke, 2006; Tracy, 2010) involving several layers of close reading and coding, with codes eventually organised into emergent themes. Analysis was led by an autistic doctoral researcher with no previous connections to the participants, with triangulation of code development with two non-autistic supervisors.

Results

Study A

Demographic characteristics and group differences of autistic and non-autistic participants are displayed in Table 1. Significant group differences were found for age (autistic group M=33.75, SD=12.43; non-autistic group M=26.72, SD=10.48; *Welch's* t(206)=-4.43, p<.001), and level of education, but not gender assigned at birth.

Table 1Demographic characteristics and group differences Study A

Demographic characteristic	Autistic	Non-Autistic	χ^2 (df)	р
	n (%)	n (%)		
Gender assigned at birth			2.32 (1)	.128
Female	58 (53.2)	64 (64)		
Male	51 (46.8)	36 (36)		
Education ^a			18.67 (4)	.001
GCSE or similar	18 (16.5)	1 (1)		
A-levels or similar	22 (20.2)	30 (30)		
Attended college, no degree	15 (13.8)	8 (8)		
Undergraduate degree	32 (29.4)	37 (37)		
Graduate degree	22 (20.2)	24 (24)		

Note. a Based on UK education system

Self-report group differences are displayed in Table 2. As predicted, autistic traits (measured by AQ) were significantly higher in the autistic than the non-autistic group.

Table 2Self-report measures and group differences

Self-report measure	Autistic		Non-autistic		<i>F</i> (df)	р
	Mean	SD	Mean	SD		_
AQ	34.94	7.55	18.35	6.21	266.00 (1, 205)	<.001
Trait anxiety	58.39	11.1	41.78	10.87	130.20 (1, 205)	<.001
Depression	12.5	6.17	5.71	4.35	74.42 (1, 205)	<.001
Loneliness	55.9	9.94	41.61	8.51	118.80 (1, 205)	<.001
Loneliness Distress	45.68	13.32	32.56	8.61	70.49 (1, 205)	<.001
Sensory Sensitivity	75.06	24.91	50.33	17.7	27.50 (1, 88)	<.001
Sensory Hypersensitivity	41.37	14.65	26.26	11.78	29.21 (1, 88)	<.001
Sensory Hyposensitivity	33.69	12.1	24.07	7.62	17.62 (1, 88)	<.001

Note. N=209 (autistic n=109, non-autistic n=100) for Demographics, AQ, STAI-T (trait anxiety), PHQ-9 (depression), UCLA-L (loneliness), UCLA-D (loneliness distress)

N=92 (autistic n=65, non-autistic n=29) for GSQ measures (sensory sensitivity)

Autistic adults displayed significantly higher trait anxiety (Figure 1A), depression (Figure 1B), loneliness (Figure 2A), loneliness distress (Figure 2B), and general sensory sensitivity (Figure 3) after controlling for age and level of education (Table 1).

Figure 1

Mental health group differences between autistic and non-autistic participants Study A. Lines show median. Dots show individual data points. Colour code for A) trait anxiety and depression B): Black=mild, dark red=moderate, red=severe

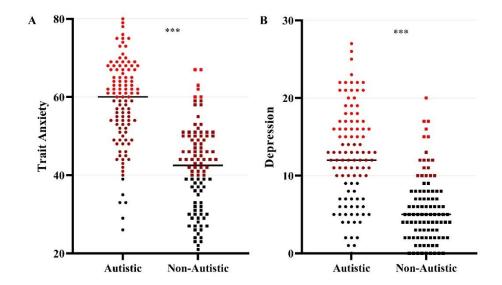


Figure 2

Loneliness group differences between autistic and non-autistic participants Study A. Lines show median. Dots show individual data points.

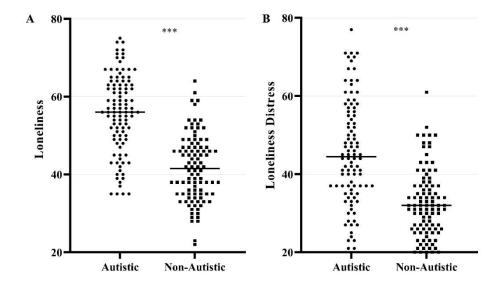
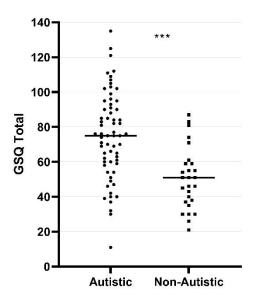


Figure 3

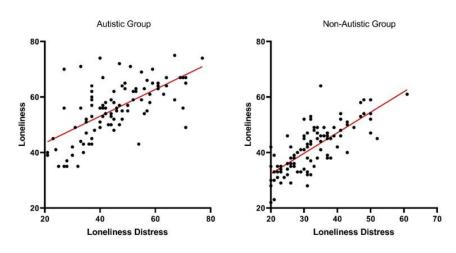
Sensory sensitivity group differences between autistic and non-autistic participants Study A. Lines show



median. Dots show individual data points.

Loneliness scores derived from the total sum of the original UCLA LS items and total sum of added distress items were highly correlated in both groups (autistic r=.647, p<.001, Figure 2; non-autistic r=.748, p<.001, Figure 4), with no statistically significant difference in the correlations of the two cohorts (z=1.40, p=.081).

Figure 4Correlations between loneliness and loneliness distress in autistic and non-autistic participants Study A.



Intercorrelations between variables in the two groups are displayed in Table 3.

Table 3Bivariate Pearson's correlations per group

Variable	1	2	3	4	5	6	7
1. Trait anxiety	-	.56***	.24*	.28**	.26	.27	.18
2. Depression	.68***	-	.23*	.28**	.30	.28	.29
3. Loneliness	.48***	.41***	-	.75**	.17	.15	.17
4. Loneliness Distress	.53***	.48***	.65***	-	18	22	07
5. Sensory Sensitivity	.46***	.26*	.30**	.10	-	.95***	.86***
6. Sensory Hypersensitivity	.46***	.25*	.29*	.13	.94***	-	.65***
7. Sensory Hyposensitivity	.40***	.24	.27*	.04	.92***	.73***	-

Note. The results for the autistic group are shown below the diagonal. The results for the non-autistic group are shown above the diagonal.

Positive correlations between anxiety, depression, loneliness and distress were found in both groups. Significant differences between correlations of autistic and non-autistic adults only occurred in correlations between loneliness, loneliness distress, and trait anxiety (Table 4), detailing greater coupling of anxiety with levels of loneliness and loneliness distress in the autistic group relative to the non-autistic group.

 Table 4

 Comparison of Pearson's Correlations between groups

Variable	1	2	3	4	5	6
1. Trait anxiety						
2. Depression	-1.352					
3. Loneliness	-2.027*	-1.409				
4. Loneliness Distress	-2.158*	-1.577	1.374			
5. Sensory Sensitivity	-0.987	0.163	-0.551	-1.140		
6. Sensory	0.001	0.124	0.506	1 456	0.020	
Hypersensitivity	-0.901	0.134	-0.586	-1.456	0.039	
7. Sensory	1.007	0.007	0.427	0.467	1 002	0.671
Hyposensitivity	-1.007	0.097	-0.437	-0.467	-1.092	-0.671

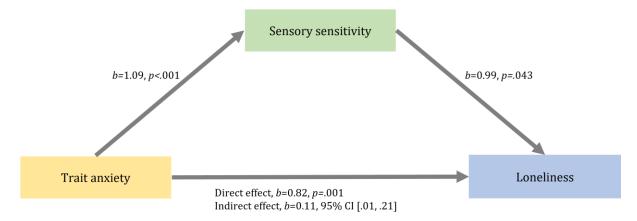
Note. **p*<.05. ***p*<.01; ****p*<.001

The mediation analysis indicated that the relationship between anxiety and loneliness was mediated by sensory sensitivity (b=0.108, 95% CI [.006, .214]), suggesting that sensory sensitivity could help explain why higher anxiety predicts higher loneliness (Figure 5), i.e., higher anxiety is associated with greater sensory sensitivities, which are in turn associated with greater loneliness.

^{*}*p*<.05. ***p*<.01; ****p*<.001

Figure 5

Mediation Analysis Study A. Sensory sensitivity as a mediator of predictor relationship between trait anxiety and loneliness. Confidence intervals for indirect effect is a bootstrapped confidence interval based on 5,000 samples.



Study B

The initial inductive analysis, involving several close readings and code-development, identified two different types of loneliness described by the autistic participants. The first type constituted a practical kind of loneliness. This included reduced opportunities to meet and spend time with other people due to financial constraints, an absence of community spaces and a reduced ability to access social spaces in urban areas:

Daphne*

"Cos I was looking out my living room window and I could see my aunt's house which is the house she used to live in. And I thought that's right over in Hampton Street*, and I could see it and I thought well from here I could walk there if it wasn't for all the roads...I could just walk over there..."

The second, and most prevalent type of loneliness that emerged from the data was a deeper yearning for meaningful connection with others and the sense that this was often out of reach:

Peter* (autistic adult with additional learning disabilities):

"Cos I feel, you know, say I'm in a group of people and they're all chatting away... cos I'm not on, I'm not on their level [...] I feel lonely *even though* I'm in that, that group: I feel lonely just sitting there."

Sarah*:

"I'm trying to reach out, I'm trying to find my people, but it's not – as you say – it's not connecting deeply within me; it all still feels a bit hopeless and superficial."

Molly*:

"I want to, like, actually like make a connection with someone..."

"...it's having people to actually talk, like talk openly to."

Difficulties in connecting with non-autistic people, difficulties in finding others with similar interests, and a lack of being either understood or accepted by wider society were all frequently cited as both causes and effects of loneliness, along with mental health issues such as anxiety and depression.

An additional deductive sweep of the data was conducted to search for participant comments that might 'support, complement, qualify, or outright contradict' (Watts, 2014) patterns identified in the quantitative findings reported above. Two further themes were identified here: the first of which was an autistic contentment in, and need for, spending time alone:

Miranda*:

"I like being on my own."

Monique*:

"I need a lot of time by myself"

Nigel*:

"I've spent a lot of time on my own: I'm quite happy on my own a lot of the time"

Sarah*:

"I'm very solitary person [...] I think my set point is about needing a lot of time for myself"

Laura*:

"I'm quite comfortable, erm, with my own company."

This taking pleasure in, and requiring time, being alone did not negate the sometimes extremely distressing experiences of loneliness reported by the autistic participants in their conversations. The need for solitude was only one part of their experiences and was often mentioned when trying to communicate what exactly it was about loneliness that was so upsetting. This first theme, then, is perhaps related to the second: The experience of being overwhelmed as a result of spending time with (non-autistic) others:

Sarah:

"Sometimes after spending much time with people... I can feel drained and like I just need some time out."

"...so actually most of the friends that I've made are actually autistic, or around somewhere on the autism spectrum, because erm, generally [they're] far more accepting of the fact that sometimes people need space?"

Marcus:

"And er, I think [my loneliness] is to do with my condition though. I just, like, I don't wanna speak to people at work sometimes it's like nooo I don't wanna speak to you just shhhhh [...] I mean, I like peace and quiet."

Miranda:

"... the other night I was in a group of people. It was all women and I struggle a bit with kind of all same sex environments sometimes? And it was a lot of people that I didn't know [...] and they were all doing things that I didn't really kind of get and it was all a bit overwhelming. I felt very overwhelmed and I felt very on the edge of it all."

Discussion

In Study A, we explored the prevalence of loneliness and associated distress in autistic and non-autistic adults. Participants also provided information on levels of anxiety, depression, and sensory hyper- and hyposensitivities. Adding an explicit measure of distress relating to loneliness allowed us to confirm that autistic adults not only displayed significantly higher levels of loneliness than non-autistic control participants, but that their level of loneliness distress was also much greater (Figure 2). This quantification of loneliness distress clearly negates the hypothesis that autistic individuals lack the motivation to seek out meaningful social relationships, refuting the implication that their loneliness is a case of chosen solitude eliciting few feelings of distress (Chevallier et al., 2012). In both autistic and non-autistic participants, loneliness and loneliness distress were highly correlated (Figure 4), which additionally supports the observation that autistic people are equally distressed by feelings of loneliness.

Levels of trait anxiety (Figure 1A) and depression (Figure 1B) were significantly higher in the autistic group. Most autistic participants displayed moderate to severe anxiety (cut offs as defined by Emons et al., 2019), and more than two thirds showed moderate to severe depression (cut offs as defined by Kroenke et al., 2001). Correlational analyses indicated that loneliness and loneliness distress were more strongly linked with levels of anxiety in autistic than non-autistic participants, again confirming that feelings of loneliness and associated distress exert detrimental effects on their mental health; a finding that is reinforced by the analysis from Study B. This is in line with previous research showing that loneliness is associated with poor mental health in both autistic and non-autistic adults (Quadt et al., 2020).

The sense of being overwhelmed was reported by participants in Study B to arise from high intensity social encounters (i.e. in groups; with strangers; in an office

environment) and might represent, in part, an anxiety response and, in part, the experience of receiving 'too much information' (to borrow the title of the National Autistic Society's campaign, 2015-2018) for processing at speed. The reported need for solitude (Study B) may thus arise, in part, as a consequence of being overwhelmed during social encounters and a result of the need for low-arousal environments. These qualitative insights are supported by the results of the mediation analysis (Figure 5), which showed that the effect of anxiety on loneliness may operate through sensory sensitivity. This means that trait anxiety may be linked with increased loneliness because augmented sensory processing could overwhelm and hinder opportunities for meaningful social interactions.

Our combined findings indicate that autistic adults are more vulnerable to the negative effects of loneliness than non-autistic adults, and that feelings of distress, which are directly associated with loneliness, are higher in the autistic than non-autistic population. Given the persisting stereotype that autistic individuals are not upset about loneliness, this is an important finding, which should be considered by the clinical and research community. Nevertheless, our findings are not at odds with the possibility that some autistic (and non-autistic) people still choose solitude, as enjoying or choosing solitude (for example to avoid sensory overload) and being distressed by feelings of loneliness are not mutually exclusive.

The exploration of increased loneliness and associated negative consequences in autistic individuals would be incomplete without considering a larger social and societal context. The term 'ethical loneliness' was coined by Stauffer (2015) to describe rejection of individuals or groups of individuals through repeated societal unethical behaviour. Although originally used in political contexts, a growing body of research confirms that autistic people indeed are 'abandoned by humanity' (Stauffer, 2015), for example when

considering the routine *othering* of autistic people (Sasson et al., 2017), or the increased risk of abuse and subsequent traumatization (Haruvi-Lamdan et al., 2020). In this context, the fundamental disconnect that many autistic individuals experience stems from an unwillingness of the neurotypical world to make space for, and include, neurodivergent individuals and groups. Although our results show that sensory sensitivities play a role in the relationship between loneliness and anxiety, it must be considered that differences in sensory processing may underlie a larger social disconnect (Williams, 2020a), and make it a clinical and societal goal to create more inclusive environments.

Our studies have several limitations. In Study A, the group size for sensory sensitivity measures was much larger (n=65) in the autistic than non-autistic (n=29) group. This was due to delays in securing amendments to the ethical approval for the original clinical trial, to enable the collection of this additional data. In the non-autistic group, the relatively low sample size could therefore have contributed to the absence of significant relationships between sensory measures and other measures. However, sensory hyper- and hyposensitivities are much more frequent in autistic than non-autistic adults (Proff et al., 2021; Ward et al., 2017), which likely explains the differences between groups. In Study B, while smaller sample sizes are more commonplace in rich qualitative research, it would be unwise to generalise too widely.

Despite the relatively large sample size of participants for affective and loneliness measures in Study A, our sample cannot be representative of the entire autism spectrum. We excluded individuals with learning disabilities that would prevent them from independently read and answer the survey, and most of our autistic participants were verbal and able to travel independently or with a carer to study facilities. Our studies therefore represent only a specific part of the autistic spectrum. Additionally, although

none of our non-autistic participants in Study A had an official diagnosis of autism or other neurodivergent conditions (such as ADHD or Tourette's Syndrome), we did not explicitly screen for those. Therefore, although on average autistic traits were below the threshold for a suspected diagnosis as measured by AQ, we cannot exclude the possibility that some of them were neurodivergent with absolute certainty.

Lastly, our modification of UCLA Loneliness Scale to incorporate distress requires more formal validation and psychometric evaluation, which is currently underway (Quadt & Bartlett, 2021).

Loneliness and associated health problems are complex and can manifest themselves on multiple levels. The effects of long-term loneliness or social isolation on physical and mental health can be explained within frameworks of social allostasis (Quadt et al., 2020) or social homeostasis (Matthews & Tye, 2019), where prolonged loneliness elicits autonomic impairments, yet societal factors underlying loneliness cannot be ignored. We therefore maintain that research and clinical translation must consider loneliness as a multidimensional issue that cannot be tackled at a single level alone.

Taken together, our studies confirm that loneliness is significantly related to feelings of distress and poor mental health in both autistic and non-autistic adults. Moreover, in autistic adults, sensory sensitivities in a world that does not accommodate for variant sensory profiles may drive autistic individuals to become increasingly isolated, contributing to feelings of loneliness. Together with considerations of ethical loneliness and the larger social and societal context, our results highlight the need for welcoming sensory environments to help minimize the disconnect that so many autistic adults experience.

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References

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5 ed.). https://doi.org/10.1176/appi.books.9780890425596
- Asztély, K., Kopp, S., Gillberg, C., Waern, M., & Bergman, S. (2019). Chronic Pain And Health-Related Quality Of Life In Women With Autism And/Or ADHD: A Prospective Longitudinal Study. *J Pain Res*, 12, 2925-2932. https://doi.org/10.2147/JPR.S212422
- Baeza-Velasco, C., Cohen, D., Hamonet, C., Vlamynck, E., Diaz, L., Cravero, C., . . . Guinchat, V. (2018).

 Autism, Joint Hypermobility-Related Disorders and Pain. *Front Psychiatry*, *9*, 656. https://doi.org/10.3389/fpsyt.2018.00656
- Bandelow, B., & Michaelis, S. (2015). Epidemiology of anxiety disorders in the 21st century. *Dialogues Clin Neurosci*, 17(3), 327-335. https://doi.org/10.31887/DCNS.2015.17.3/bbandelow
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from asperger syndrome/high-functioning autism, malesand females, scientists and mathematicians. *Journal of autism and developmental disorders*, 31(1), 5-17.
- Bauminger, N., & Kasari, C. (2000, Mar-Apr). Loneliness and friendship in high-functioning children with autism. *Child Dev, 71*(2), 447-456. https://doi.org/10.1111/1467-8624.00156
- Bauminger, N., Solomon, M., Aviezer, A., Heung, K., Gazit, L., Brown, J., & Rogers, S. J. (2008). Children with autism and their friends: A multidimensional study of friendship in high-functioning autism spectrum disorder. *Journal of abnormal child psychology*, *36*(2), 135-150.
- Beardon, L. (2017). Autism and Asperger syndrome in adults. Sheldon Press.
- Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). Avoiding ableist language: Suggestions for autism researchers. *Autism Adulthood*, *3*(1), 18-29. https://doi.org/10.1089/aut.2020.0014
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa
- Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *J Autism Dev Disord*, 44(12), 3063-3071. https://doi.org/10.1007/s10803-014-2170-2
- Cacioppo, S., Grippo, A. J., London, S., Goossens, L., & Cacioppo, J. T. (2015, Mar). Loneliness: clinical import and interventions. *Perspect Psychol Sci, 10*(2), 238-249. https://doi.org/10.1177/1745691615570616
- Casanova, E., Sharp, J., Edelson, S., Kelly, D., Sokhadze, E., & Casanova, M. (2020). Immune, Autonomic, and Endocrine Dysregulation in Autism and Ehlers-Danlos Syndrome/Hypermobility Spectrum Disorders Versus Unaffected Controls. *Journal for ReAttach Therapy and Developmental Diversities*, 2(2), 82-95.

- Causton-Theoharis, J., Ashby, C., & Cosier, M. (2009). Islands of loneliness: exploring social interaction through the autobiographies of individuals with autism. *Intellectual and Developmental Disabilities*, *47*(2), 84-96. https://doi.org/10.1352/1934-9556-47.2.84
- Chevallier, C., Kohls, G., Troiani, V., Brodkin, E. S., & Schultz, R. T. (2012). The social motivation theory of autism. *Trends in cognitive sciences,* 16(4), 231-239. https://doi.org/10.1016/j.tics.2012.02.007
- Csecs, J. L. L., Iodice, V., Rae, C. L., Brooke, A., Simmons, R., Quadt, L., . . . Eccles, J. A. (2022, 2022-February-02). Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain [Original Research]. *Frontiers in Psychiatry*, *12*. https://doi.org/10.3389/fpsyt.2021.786916
- de Jong Gierveld, J., & Tilburg, T. V. (2006). A 6-Item Scale for Overall, Emotional, and Social Loneliness: Confirmatory Tests on Survey Data. *Research on Aging, 28*(5), 582-598. https://doi.org/10.1177/0164027506289723
- de Jong Gierveld, J., & Van Tilburg, T. (1999). Manual of the loneliness scale. *Amsterdam: Department of Social Research Methodology*.
- DiTommaso, E., & Spinner, B. (1993). The development and initial validation of the Social and Emotional Loneliness Scale for Adults (SELSA). *Personality and individual differences, 14*(1), 127-134. https://doi.org/10.1016/0191-8869(93)90182-3
- Ee, D., Hwang, Y. I., Reppermund, S., Srasuebkul, P., Trollor, J. N., Foley, K.-R., & Arnold, S. R. (2019). Loneliness in Adults on the Autism Spectrum. *Autism in Adulthood*, 1(3), 182-193. https://doi.org/10.1089/aut.2018.0038
- Emons, W. H., Habibović, M., & Pedersen, S. S. (2019). Prevalence of anxiety in patients with an implantable cardioverter defibrillator: measurement equivalence of the HADS-A and the STAI-S. Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation, 28(11), 3107-3116. https://doi.org/10.1007/s11136-019-02237-2
- Fletcher-Watson, S., & Happe, F. (2019). *Autism: A New Introduction to Psychological Theory and Current Debate*. Routledge.
- Haruvi-Lamdan, N., Horesh, D., Zohar, S., Kraus, M., & Golan, O. (2020). Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of conditions. *Autism*, *24*(4), 884-898. https://doi.org/10.1177/1362361320912143
- [Record #3425 is using a reference type undefined in this output style.]
- Hedley, D., Uljarevic, M., Foley, K. R., Richdale, A., & Trollor, J. (2018a, Jul). Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder. *Depress Anxiety*, 35(7), 648-657. https://doi.org/10.1002/da.22759
- Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C. (2018b). Understanding depression and thoughts of self-harm in autism: a potential mechanism involving loneliness. *Research in Autism Spectrum Disorders*, 46, 1-7.

- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019, Mar). Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychol Med*, 49(4), 559-572. https://doi.org/10.1017/S0033291718002283
- Hudson, C. C., Hall, L., & Harkness, K. L. (2019, 2019-01-01). Prevalence of Depressive Disorders in Individuals with Autism Spectrum Disorder: a Meta-Analysis. *Journal of abnormal child psychology*, *47*(1), 165-175. https://doi.org/10.1007/s10802-018-0402-1
- Jaswal, V. K., & Akhtar, N. (2019). Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences, 42*, e82, Article e82. https://doi.org/10.1017/S0140525X18001826
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*, 16(9), 606-613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x
- Lenhard, W., & Lenhard, A. (2014). *Hypothesis tests for comparing correlations. Retrieved from https://www.psychometrica.de/correlation.html*. Psychometrica. https://doi.org/10.13140/RG.2.1.2954.1367
- Lin, L. Y., & Huang, P. C. (2019, Apr). Quality of life and its related factors for adults with autism spectrum disorder. *Disabil Rehabil, 41*(8), 896-903. https://doi.org/10.1080/09638288.2017.1414887
- Matthews, G. A., & Tye, K. M. (2019). Neural mechanisms of social homeostasis. *Annals of the New York Academy of Sciences*, 1457(1), 5-25. https://doi.org/10.1111/nyas.14016
- Mazurek, M. O. (2014, Apr). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism*, 18(3), 223-232. https://doi.org/10.1177/1362361312474121
- Milton, D., & Bracher, M. (2013). Autistics speak but are they heard. *Journal of the BSA Medsoc Group,* 7, 61-69.
- Milton, D., Heasman, B., & Sheppard, E. (2018). Double empathy. *Encyclopedia of autism spectrum disorders*.
- Milton, D. E. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society, 27*(6), 883-887.
- Muskett, A., Radtke, S., White, S., & Ollendick, T. (2019). Autism Spectrum Disorder and Specific Phobia: the Role of Sensory Sensitivity: Brief Review. *Review Journal of Autism and Developmental Disorders*, 6(3), 289-293. https://doi.org/10.1007/s40489-019-00159-w
- National Autistic Society, U. (2018). *Hidden crisis: Autistic people four times more likely to be lonely than general public*. Retrieved 28/09/2019 from https://www.autism.org.uk/get-involved/media-centre/news/2018-04-25-hidden-crisis-autism-and-loneliness.aspx
- Proff, I., Williams, G. L., Quadt, L., & Garfinkel, S. N. (2021). Sensory processing in autism across exteroceptive and interoceptive domains. *Psychology & Neuroscience*. https://doi.org/10.1037/pne0000262

- QSR International Pty Ltd. (2020). *NVivo* (*Released in March 2020*). *Available online at https://www.qsrinternational.com/nvivo-qualitative-data-analysissoftware/home*.
- Quadt, L., & Bartlett, J. (2021, July 7). Development and Validation of a Modified Version of the UCLA Loneliness Scale: UCLA Loneliness, Distress, and Contentment Scale (UCLA-LDC). https://doi.org/10.17605/OSF.IO/642RN
- Quadt, L., Esposito, G., Critchley, H. D., & Garfinkel, S. N. (2020). Brain-body interactions underlying the association of loneliness with mental and physical health. *Neuroscience & Biobehavioral Reviews*, *116*, 283-300. https://doi.org/10.1016/j.neubiorev.2020.06.015
- Quadt, L., Garfinkel, S. N., Mulcahy, J. S., Larsson, D. E. O., Silva, M., Jones, A.-M., . . . Critchley, H. D. (2021). Interoceptive training to target anxiety in autistic adults (ADIE): A single-center, superiority randomized controlled trial. *EClinicalMedicine*, *39*, 101042. https://doi.org/10.1016/j.eclinm.2021.101042
- Robertson, A. E., & Simmons, D. R. (2013). The relationship between sensory sensitivity and autistic traits in the general population. *Journal of autism and developmental disorders, 43*(4), 775-784.
- Russell, D. W. (1996). UCLA Loneliness Scale (Version 3): reliability, validity, and factor structure.

 Journal of personality assessment, 66(1), 20-40.

 https://doi.org/10.1207/s15327752jpa6601_2
- Rydzewska, E., Hughes-McCormack, L. A., Gillberg, C., Henderson, A., MacIntyre, C., Rintoul, J., & Cooper, S. A. (2018, Sep 1). Prevalence of long-term health conditions in adults with autism: observational study of a whole country population. *BMJ Open, 8*(8), e023945. https://doi.org/10.1136/bmjopen-2018-023945
- Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical Peers are Less Willing to Interact with Those with Autism based on Thin Slice Judgments. *Scientific Reports, 7*(1), 40700. https://doi.org/10.1038/srep40700
- South, M., & Rodgers, J. (2017). Sensory, Emotional and Cognitive Contributions to Anxiety in Autism Spectrum Disorders [Mini Review]. *Front Hum Neurosci*, 11(20). https://doi.org/10.3389/fnhum.2017.00020
- Spielberger, C. D. (2010). State-Trait anxiety inventory. The Corsini encyclopedia of psychology, 1-1.
- Stauffer, J. (2015). Ethical loneliness: The injustice of not being heard. Columbia University Press.
- Sunwoo, M., O'Connell, J., Brown, E., Lin, A., Wood, S. J., McGorry, P., & O'Donoghue, B. (2020, Feb). Prevalence and outcomes of young people with concurrent autism spectrum disorder and first episode of psychosis. *Schizophr Res, 216,* 310-315. https://doi.org/10.1016/j.schres.2019.11.037
- Syu, Y.-C., & Lin, L.-Y. (2018). Sensory Overresponsivity, Loneliness, and Anxiety in Taiwanese Adults with Autism Spectrum Disorder. *Occupational therapy international, 2018*, 9165978-9165978. https://doi.org/10.1155/2018/9165978

- Tavassoli, T., Miller, L. J., Schoen, S. A., Nielsen, D. M., & Baron-Cohen, S. (2013). Sensory over-responsivity in adults with autism spectrum conditions. *Autism*, *18*(4), 428-432. https://doi.org/10.1177/1362361313477246
- Tracy, S. J. (2010). Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research. *Qualitative Inquiry, 16*(10), 837-851. https://doi.org/10.1177/1077800410383121
- Valtorta, N. K., Kanaan, M., Gilbody, S., & Hanratty, B. (2016). Loneliness, social isolation and social relationships: what are we measuring? A novel framework for classifying and comparing tools. *BMJ Open*, *6*(4), e010799. https://doi.org/10.1136/bmjopen-2015-010799
- Ward, J., Hoadley, C., Hughes, J. E. A., Smith, P., Allison, C., Baron-Cohen, S., & Simner, J. (2017). Atypical sensory sensitivity as a shared feature between synaesthesia and autism. *Scientific Reports*, 7(1), 41155. https://doi.org/10.1038/srep41155
- Watts, S. (2014). User Skills for Qualitative Analysis: Perspective, Interpretation and the Delivery of Impact. Qualitative Research in Psychology, 11(1), 1-14. https://doi.org/10.1080/14780887.2013.776156
- Weiss, R. S. (1973). Loneliness: The experience of emotional and social isolation. MIT Press.
- White, S. W., & Roberson-Nay, R. (2009, Jul). Anxiety, social deficits, and loneliness in youth with autism spectrum disorders. *J Autism Dev Disord*, 39(7), 1006-1013. https://doi.org/10.1007/s10803-009-0713-8
- Williams, G. (2020a). Perceptual deviants: understanding autistic subjectivities in a (not so) predictable world. In D. Milton, D. Murray, N. Martin, S. Ridout, & R. Mills (Eds.), *The Neurodiversity Reader: Exploring concepts, lived experience and implications for practice* (pp. 35-40). Pavillion Publishing.
- Williams, G. L. (2020b). From anonymous subject to engaged stakeholder: Enriching participant experience in autistic-language-use research. *Research for All, 4*(2), 314-328. https://doi.org/10.14324/RFA.04.2.13
- Williams, G. L., Wharton, T., & Jagoe, C. (2021). Mutual (Mis)understanding: Reframing Autistic Pragmatic "Impairments" Using Relevance Theory [Original Research]. *Frontiers in psychology*, 12(1277). https://doi.org/10.3389/fpsyg.2021.616664