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Original Research

Loneliness in Adults on the Autism Spectrum

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Abstract

Background: Loneliness is associated with adverse psychological and physical outcomes. However, little is known about the factors contributing to loneliness in autistic adults. This study aimed to quantitatively compare levels and predictors of loneliness in autistic and nonautistic adults, and then contextualize these findings by thematically analyzing responses to open-ended questions on autistic adults' socialization experiences.
Methods: We obtained data from the Cooperative Research Centre for Living with Autism (Autism CRC) Australian Longitudinal Study of Adults with Autism (ALSAA). The sample comprised 220 autistic adults (age mean [*M*] = 41.9 years, standard deviation [SD] = 12.24) and 146 nonautistic adults (age *M* = 43.7 years, SD = 13.49). We measured loneliness with the University of California, Los Angeles (UCLA) loneliness scale (ULS-8). We compared the findings between these two groups of adults. Through regression models, we investigated associations between loneliness and demographics, autistic traits, social support, depression, anxiety, and self-efficacy. We adapted these determinants from De Jong-Gierveld's model of loneliness. In addition, we conducted an inductive thematic analysis of autistic participants' open-ended responses about their socialization. We used an inclusive approach utilizing an advisory panel of autistic adults in study design and interpretations.
Results: Autistic adults scored significantly higher on the ULS-8 than nonautistic adults ($p < 0.001$). The presence of autism contributed the greatest variance in the loneliness score ($B = 8.11$, 95% confidence interval [6.98–9.23], $p < 0.001$, $R^2 = 0.38$). The autism quotient subdomains of social skills and dissatisfaction with social support were associated with greater loneliness in both autistic and nonautistic groups ($p < 0.05$). The thematic analysis contextualized the interpretation of quantitative findings, specifically regarding perceived loneliness and difficulties with social interaction. Satisfaction and perceptions of socialization were widely variable and both of which were shaped by experiences. Environmental factors, noise in particular, as well as social communication difficulties and past negative experiences seemed to be the barriers to socialization.
Conclusions: Autistic adults have reported higher levels of loneliness. Variables associated with loneliness in both groups were dissatisfaction with social support and the autism quotient subdomain of social skills. The subjectivity of perceived loneliness, views about socialization, and their implications for social support in autistic adults warrant further study.

Keywords: autism, loneliness, adult, social support, social network, social skills

Lay Summary

Why was this study done?

Loneliness is a negative feeling of not having intimacy and desired relationships. Loneliness is related to depression, anxiety, and even cardiovascular risk among other negative impacts. Little is known about loneliness in autistic adults. No research has been done on this topic that used a validated questionnaire and a community comparison group.

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What was the purpose of this study?

To understand what was associated with loneliness in autistic adults compared with nonautistic adults. We also wanted to understand the experience of loneliness for autistic adults.

What did the researchers do?

We used data from the Australian Longitudinal Study of Adults with Autism (ALSAA). The ALSAA study gathers questionnaires from both autistic ($n = 252$) and nonautistic adults ($n = 146$) aged 25+ years (mean [M] = 42.6, standard deviation [SD] = 12.8) from across Australia. We used various questionnaires from the ALSAA to look at factors related to loneliness. We also looked at the comments autistic adults made about the way they socialize.

What were the results of the study?

Autistic adults are often lonelier than nonautistic adults. Loneliness for both autistic and nonautistic adults was related to social skills and dissatisfaction with social support. However, autistic adults told us that there is a difference between loneliness and being alone, so we have to be careful when interpreting our questionnaire data. Autistic adults also told us there are many barriers to socializing, for example, noisy environments or a culture of drinking alcohol. They told us that socializing with nonautistic adults can be exhausting, challenging, or anxiety provoking. Some said that socializing was unnecessary. Some were bullied that gave them a negative impression of socializing. Some autistic adults said that a quiet setting, sport, or recreation activities can support them to socialize more.

What do these findings add to what was already known?

These findings help us understand loneliness for autistic adults better, but more research needs to be done. We confirmed autistic adults are often lonelier.

What are potential weaknesses in the study?

Participants in the ALSAA study were self-selected rather than sampled randomly. This could mean that the nonautistic participants may have more interest in autism than the general population. Because participants needed to be able to read and understand the survey, autistic participants do not represent the full range of people on the autism spectrum and people with intellectual disability may be excluded. We do not have longitudinal data, that is, data from more than one point in time, so we cannot be sure of what causes loneliness. We only used a short version of the loneliness questionnaire. We did not ask the autistic adults enough questions about their experiences of loneliness. Soon the ALSAA study will have data from more than one point in time, and data using the long version of the loneliness questionnaire.

How will these findings help autistic adults now or in the future?

These findings show that loneliness is more frequent for autistic adults. These findings suggest that maybe strategies to help with loneliness for nonautistic adults could help some autistic adults. As we start to understand loneliness and aloneness in autistic adults better, we can do a better job designing strategies to help people be less lonely.

Introduction

Loneliness may be defined by two central characteristics: an experience of negative affect resulting from feelings of absence of intimacy and a judgment of discrepancy, whether quantitative or qualitative, between one's desired and perceived actual relationships.[1,2] Loneliness is associated with numerous adverse psychological and physiological consequences, including depression, anxiety, anger, poor cognition, low self-esteem, and cardiovascular risk.[3] The core characteristics of autism suggest a potential for loneliness if the dissimilarity in social norms in social interaction and communication, or restricted or repetitive patterns of behavior, impacts on relationship formation and intimacy.[2,4–7] Indeed, studies have shown that autistic children and adolescents tend to be lonelier than nonautistic counterparts.[4,8–12] However, only one study has examined autistic adults, and reported them as being lonelier than nonautistic adults despite their desire for friendship.[3]

Although the literature on loneliness in autistic adults is limited, studies have identified several factors associated with loneliness in younger individuals. These factors may be organized to reflect the prominent causal model of loneliness developed by De Jong-Gierveld for the general population. The model comprised four domains: (1) social structural characteristics (age, gender, relationship status, living arrangement, and employment), (2) social network characteristics (friends and contact), (3) cognitive appraisal of one's

social network (self-evaluated satisfaction and support), and (4) personality characteristics (concept of self, social anxiety, introversion/extraversion).[1,2] To date, no focused investigation of this model has been undertaken in an autistic sample. Although we cannot assume that these general determinants will be replicated in the autistic population, the model does provide a framework for investigating loneliness in autistic adults.

According to the model, poorer social network characteristics contributed to loneliness in the general population.[13] These characteristics remain inadequately studied in autistic adults, but social networks were smaller in autistic adult samples of Dutch and Americans.[3,8] Friendships were even nonexistent for 46.4% of the 235 American autistic adolescents and adults.[8] Having more friends or a close friend has been associated with reduced loneliness in autistic adults, but the impacts of contact frequency with friends and family are unknown.[9]

Overlying this is the subjective cognitive appraisal of one's social network that moderates the impact of social network characteristics.[3] In a study of children and adolescents, autistic participants perceived their friendships as lower quality than nonautistic peers.[7] In this age group, two factors contributed to positive appraisal of social network. Female gender was associated with higher friendship quality ratings.[4,10–12] Support from parents and peers had stronger association with decreased loneliness than support from teachers.[14] Similarly, another study showed that autistic adults were less often satisfied with their social networks than nonautistic adults or adults with intellectual disability.[15]

Social structural characteristics would also be a consideration in our investigation. This variable shapes the socialization opportunities of individuals.[9] The causal model explains that in the general population, the absence of a living partner was the greatest predictive factor for loneliness, whereas other variables, namely age, gender, employment status, and living arrangement, were less influential.[13] The associations of these variables with loneliness in autistic adults are yet to be determined.

Finally, we would regard personality characteristics: a determinant that may influence one's social behaviors and perception of loneliness.[13] In the nonautistic population, lower self-esteem (measured by self-evaluation scale[16]) predicted loneliness, whereas social anxiety and introversion were minor predictors.[13] Conceptually, shyness was also thought to increase loneliness.[17] In autistic adults, depression and anxiety have known to be associated with loneliness, but other personality characteristics have not been assessed.[18]

Given the present limitations in understanding of autistic adults and loneliness, this study aims to investigate the presence and experience of loneliness in autistic adults relative to nonautistic adults and its association with a range of demographic, psychological, and social variables using the investigative framework already described. In addition, this study analyzes participants' open-ended responses to gain a deeper understanding of loneliness in autistic adults.

Methods

Participants

The time one sample of the Cooperative Research Centre for Living with Autism (Autism CRC) ALSAA was used in this study.* The ALSAA study aimed to profile the physical and mental health, well-being, productivity, and societal participation of autistic adults, aged ≥ 25 years. This undertaking was approved by the Human Research Ethics Committee at the University of New South Wales (No. HC15001). We recruited participants nationwide through autism-specific and disability organizations, employment services, allied health practices, universities, vocational institutes, carer organizations, autism self-advocacy groups, and online autism communities. We screened interested individuals for eligibility and distributed a self-report questionnaire.

Inclusion criteria were adults >25 years, Australian residents, basic proficiency in English, and a formal diagnosis of autism in the autistic group. Thirty-two participants without a formal diagnosis were excluded. The final sample consisted of 220 autistic adults aged 25–80 years ($M = 41.9$, SD = 12.24) and 146 nonautistic adults aged 25–79 years ($M = 43.7$, SD = 13.49).

Inclusive research approach

ALSAA questionnaires were designed through an inclusive research approach.[19] Autistic advisors reviewed the language and formatting of questionnaires to verify their accessibility. Summarized research findings were given to autistic advisors for their feedback; this feedback was incorporated into the applications of findings. This prompted the inclusion of a qualitative analysis.

Measures

Loneliness. We assessed loneliness with the 8-item UCLA loneliness scale (ULS-8), a shorter version of the ULS-20 developed by Russell et al.[5] It is validated in the general population and highly correlated with the ULS-20 ($r = 0.91$).[19] The ULS-8 includes eight self-rated items on a 4-point Likert scale (''often,'' ''sometimes,'' ''rarely,'' or ''never''). These include negatively worded items correlated with loneliness such as ''There is no one I can turn to,'' along with positively worded or nonlonely items like ''I am an outgoing person.'' The total score of the scale is the sum of the items, with positively worded items reversed. Participants were given the opportunity to add open-ended comments about ''how you socialize.''

Social structural characteristics. *Autistic traits.* We measured autistic traits with the abridged autism-spectrum quotient, autism quotient score (AQ)-short,[20] a 28-item measure that has been validated for quick reliable assessment of autistic traits.[22] The two major domains, assessed on a 4-point Likert scale, are social behavioral difficulties, with subdomains of social skills (seven items, e.g., ''I find it hard to make new friends''), routine (four items, e.g., ''I prefer to do things the same way over and over again''), attention switching (four items, e.g., ''I frequently get strongly absorbed in one thing''), and imagination (eight items, e.g., ''Reading a story, I find it difficult to work out the character's intentions''), and fascination for numbers/patterns (five items, e.g., ''I am fascinated by numbers'').

*Arnold SRC, Foley K-R, Hwang YI, et al. Cohort profile: The Australian Longitudinal Study of Adults with Autism (ALSAA). 2019 (Submitted manuscript).

Characteristics of social network and cognitive appraisal of social network. *Frequency of contact.* We took items measuring frequency of contact with friends and family from the National Survey of Mental Health and Wellbeing.[21]

Social support. We used a 6-item extract of the social support questionnaire to assess the objective and subjective social support.[22] Each item consists of two parts: the first is the number of people whom the individual feels able to rely on in situations of need, that is, ''Who can you count on to console you when you are very upset?'' The second assesses satisfaction with this support, measured on a 6-point Likert scale from ''very dissatisfied'' to ''very satisfied,'' addressing perceptions of support, conflict, and relationship depth.[23]

Personality characteristics. *Depression.* We adopted the Patient Health Questionnaire-9, a self-administered depression scale.[22] It is commonly used to assess and monitor depression severity and has been validated in autistic adults.[24] Nine items are rated on a 4-point Likert scale. A cut-point of 10 or greater is considered potentially clinically significant.[25]

Anxiety. Anxiety was measured by the Severity Measure for Generalised Anxiety Disorder-Adult that corresponds closely to the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) criteria for generalized anxiety disorder.[25] It includes 10 items on a 5-point Likert scale. The total raw score can be averaged to categorize the severity of an individual's anxiety into (0), mild (1), moderate (2), severe (3), or extreme (4).[26]

Self-efficacy. We measured this with the New General Self-Efficacy (NGSE) scale. The scale consists of eight items on a 5-point Likert scale to assess GSE. This is defined as ''one's belief in one's overall competence to effect requisite performances across a wide variety of achievement situations.''[26] The NGSE is shorter but demonstrates higher construct validity than the GSE scale.[27]

Data analyses

Quantitative analyses. We compared the demographic characteristics of participants with and without missing data to assess for factors associated with noncompletion. No significant differences were found. Multiple imputation was employed with 20 imputations, predictive mean matching with 10 closest near neighbors for continuous variables,[28] logistic and polynomial logistic regression for categorical variables, and random seed set to 4321.

We explored the demographic information through descriptive statistics. Differences between autistic and nonautistic groups at baseline were determined by chi-square and *t*-test. Univariate and multiple linear regression analyses assessed the effect of autism diagnosis in association with ULS-8 score. We also assessed interactions between autism diagnosis and other variables. In subsequent analyses, we examined the autistic and nonautistic participants separately. Correlations and univariate linear regressions assessed each variable measure with the ULS-8 score. Multiple regressions with robust estimation method incorporated all variables to assess the model of loneliness determinants as a whole. These were analyzed with and without inclusion of nonbinary gender participants ($n = 10$), due to interest in gender effects and small numbers in the nonbinary gender group. We verified assumptions regarding collinearity and normality. In these analyses, we excluded AQ total to avoid multi-collinearity when analyzing subscale components. We performed all statistical analyses using Stata Statistical Software version 14, with level of significance <0.05.[27] Family-wise alpha was not adjusted due to the possibility of reducing probability of detecting true positive results.[29] *Post hoc* power calculation using the *R*-squared from the model suggested sufficient sample size for the number of variables in the regression models (>80%).

Qualitative analysis

Thematic analysis identified themes relating to socialization or loneliness, based on optional open-ended responses to ''further comments about how you socialize.'' We conducted these analyses on autistic participant responses only ($n = 68$); comments by nine nonautistic participants were inadequate to conduct a meaningful analysis.

Unlike in the quantitative analysis, wherein we presented findings within the causal theoretical framework of De Jong, we undertook an inductive approach to analyzing the qualitative data. We derived themes from the data itself to avoid theoretical bias in predetermining themes.[30] The purpose of this approach was to best capture the authentic voices of autistic participants to complement the structured quantitative analysis. We identified these themes semantically—data were organized according to their explicit meanings and summarized. The step-by-step approach involved first generating as many initial codes as semantic content was identified. Next, the codes were considered for grouping into overarching themes and subthemes. We then reviewed the themes: closely linked themes were collapsed (e.g., ''anxiety-provoking'' and ''traumatic'') and collated extracts under each theme were reassessed for pattern coherence. We excluded five comments because they did not relate to the question or were an isolated comment outside of a theme. A second author repeated the search for alternative themes and verified existing themes. An independent research assistant conducted an audit trail of coding that yielded an inter-rater reliability of 82.3%. Mismatches were discussed and reconciled between the two coders to yield 99% agreement. Another author verified the final code mismatch. Lastly, themes were refined in definition. We interpreted the patterns and related them to theoretical concepts to conclude broader meaning and implication.

Results

Participant characteristics are described in Table 1. The autistic and nonautistic groups were similar in age ($M = 42.6$, $SD = 12.8$). The nonautistic group differed significantly on demographic variables being largely female, married, or de facto, living with their partner, and employed. The autistic group had a slight female predominance, almost half had a current partner (married/de facto or girlfriend/boyfriend), and the majority also living with their partner, although other living arrangements were more common. The severity of depressive and anxiety symptoms was significantly higher in the autistic group.

Figure 1 illustrates the distribution of ULS-8 scores for autistic and nonautistic groups. The median (Mdn) score was higher in the autistic group (Mdn = 24, interquartile range

Table 1. Sample Characteristics of Participants Completing the Australian Longitudinal Study of Adults with Autism Self-Report Questionnaire

	Autistic		*Nonautistic*			
Variable	n	%	n	%	*Statistic*	p
Gender						
Male	86	39.1	29	19.9	χ^2 (4, $n = 398$) = 26.35	<0.001***
Female	124	56.4	117	80.1		
Other	10	4.5	0			
Age, mean (SD)	41.9 (12.2)		43.7 (13.5)		T (364) = 1.370	0.171
Relationship status						
Single	82	37.3	27	18.6	χ^2 (3, $n = 365$) = 28.35	<0.001***
Married/de facto	99	45.0	106	73.1		
Divorced	33	15.0	11	7.6		
Girlfriend/boyfriend	6	2.7	1	0.7		
Missing			1			
Living arrangement						
Alone	60	27.5	26	17.9	χ^2 (5, $n = 363$) = 32.01	<0.001***
With partner	100	45.9	106	73.1		
With parents	31	14.2	5	3.4		
With relatives	3	1.4	3	2.1		
With others	20	9.2	5	3.4		
Other arrangement	4	1.8	0	0		
Missing	2					
Education						
Below year 12	11	5.1	1	0.7	χ^2 (2, $n = 353$) = 6.70	0.035*
Year 12	12	5.6	4	2.9		
Further education	19	89.2	134	96.4		
Missing	6		7			
Employment status						
Employed	118	44.3	105	75.5	χ^2 (1, $n = 351$) = 14.32	<0.001***
Missing						
Intellectual disability						
Diagnosed	10	4.5	1	0.7	χ^2 (1, $n = 366$) = 4.49	0.034*
Autism diagnoses						
Autism or autism spectrum						
Disorder/condition	49	22.6				
Autistic disorder	1	0.5				
Asperger's disorder	132	60.8				
PDD-NOS	1	0.5				
Infantile autism	1	0.5				
High-functioning autism	33	15.2				
Missing	3					
Total AQ score, mean (SD)	87.6 (10.3)		55.1 (11.6)		T (344) = 26.96	<0.001***
Missing	11		9			
PHQ-9 depression scale, mean (SD)	10.4 (7.0)		4.3 (4.6)		T (322) = −8.67	<0.001***
Threshold for diagnosis met	102	51.5	15	11.9	χ^2 (1, $n = 324$) = 52.36	<0.001***
Missing	22		20			
DSM-5 Generalised Anxiety Disorder Scale, mean (SD)	14.0 (8.4)		5.6 (5.6)		T (333) = −10.07	<0.001***
Missing	15		16			
Totals ($n = 264$)	220		146			

*$p < 0.05$, ***$p < 0.001$.

AQ, autism quotient score; DSM-5, Diagnostic and Statistical Manual of Mental Disorders Fifth Edition; PDD-NOS, pervasive developmental disorder-not otherwise specified; PHQ-9, Patient Health Questionnaire 9; SD, standard deviation.

[IQR] = 7) than in the nonautistic group (Mdn = 14, IQR = 7) ($p < 0.001$).

Effect of autism diagnosis

Having an autism diagnosis accounted for 38% of the variance in the univariate regression with loneliness (B = 8.11, 95% confidence interval [CI] [6.98–9.23], $p < 0.001$, $R^2 = 0.38$). A multiple regression involving all the variables studied except for autism diagnosis accounted for 68% of the variance in loneliness (adj $R^2 = 0.68$). When autism diagnosis was added as a factor, the variance marginally increased to 69% ($B = 3.23$, 95% CI [1.35–5.11], $p = 0.001$, adj $R^2 = 0.69$) (Table 2).

There was a significant interaction between autism diagnosis and gender. Over the entire sample, excluding nonbinary

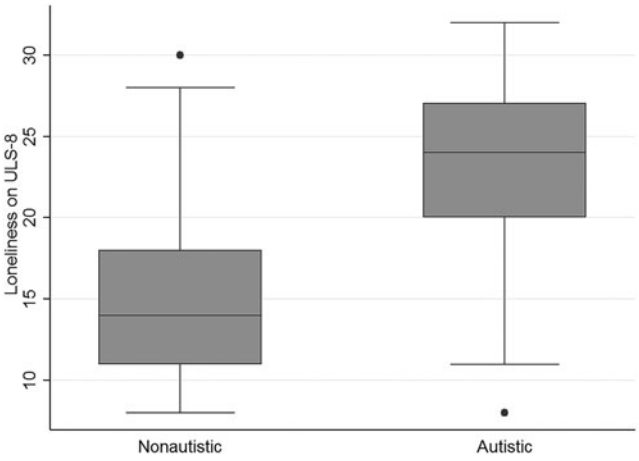

FIG. 1. Distribution of ULS-8 scores in autistic and nonautistic groups. ULS-8, UCLA 8-item loneliness scale.

participants, female gender was associated with loneliness ($B = 1.58$, $p = 0.029$); however, for autistic adults, female gender was associated with less loneliness ($B = -2.62$, $p = 0.004$). Other interactions with autism diagnosis were not significant and hence omitted from the final model. Alongside having a diagnosis of autism, AQ-short social skills ($B = 0.25$, $p = < 0.001$), AQ-short attention switching ($B = 0.99$, $p = 0.035$), and anxiety ($B = 0.13$, $p = 0.006$) were significantly associated with loneliness, whereas the number of support persons ($B = -0.38$, $p = 0.005$) and satisfaction with social support ($B = -1.61$, $p < 0.001$) were associated with less loneliness in the whole sample. Including nonbinary gender participants, frequency of contact with friends ($B = -0.361$, $p = 0.048$) became significant and AQ-short attention switching was no longer significant.

Factors affecting loneliness

Univariate regression analyses of autistic and nonautistic groups are reported in Table 3. Most factors in both the autistic and nonautistic groups had a significant association with loneliness, including stronger autistic traits, less contact with friends or family, fewer support persons and less satisfaction therewith, higher scores of depression and anxiety, and reduced self-efficacy. In the autistic group only, unemployment was significantly associated with loneliness ($B = -1.45$, $p = 0.045$).

Multiple regression analyses of autistic and nonautistic groups are reported in Table 4 (Fig. 2). The multiple regression analysis in the autistic group explained 42% of variance. Dissatisfaction with social support ($B = -1.44$, $p < 0.001$) and anxiety ($B = 0.12$, $p = 0.033$) were significantly associated with loneliness. When nonbinary gender participants were included, AQ-short social skills became significant ($B = 0.20$, $p = 0.048$)

Table 2. Multiple Regression Analyses to Predict Loneliness on UCLA 8-Item Loneliness Scale in the Entire Study Sample with Autism Diagnosis as a Factor

	B	*95% CI*	p
Social structural characteristics			
Diagnosis of autism	3.235	1.35–5.11	0.001**
Gender			
Female	1.582	0.163–3.00	0.029*
Interaction: being female with autism diagnosis	−2.62	−4.42 to −0.82	0.004**
Relationship status			
With partner	−1.158	−2.34 to 0.023	0.055
Age	−0.002	−0.04 to 0.04	0.923
Living arrangement	0.198	−1.17 to 1.57	0.776
With partner, family, or others			
Autism severity			
Social behavior			
Social skill	0.247	0.12–0.37	<0.001***
Routine	−0.510	−1.43 to 0.41	0.274
Switching	0.992	0.07–1.91	0.035*
Imagination	−0.278	−1.20 to 0.64	0.553
Factor numbers and patterns	0.078	−0.06 to 0.22	0.285
Employment status	0.477	−0.50 to 1.46	0.338
Employed			
Characteristics of social network			
Frequency of contact with family	−0.108	−0.43 to 0.21	0.503
Frequency of contact with friends	−0.347	−0.71 to 0.02	0.061†
Number of support persons SSQN score	−0.383	−0.65 to −0.119	0.005**
Cognitive appraisal of social network			
Satisfaction with support persons SSQS score	−1.606	−2.04 to −1.17	<0.001***
Personality characteristics			
Depression (PHQ-9)	−0.004	−0.12 to 0.11	0.945
Anxiety (DSM-5)	0.127	0.04–0.22	0.006**
Self-efficacy (NGSE)	0.265	−0.35 to 0.88	0.395

Adjusted $R^2 = 0.69$; *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$, †$p < 0.05$ if nonbinary gender participants included.

CI, confidence interval; NGSE, New General Self-Efficacy Scale; SSQN, Social Support Questionnaire—Number of support persons; SSQS, Social Support Questionnaire—Satisfaction with support.

Table 3. Univariate Regression Analyses to Predict Loneliness on UCLA 8-Item Loneliness Scale in Autistic and Nonautistic Groups

	Autistic (n = 220)				*Nonautistic (n = 108)*			
	B	*95% CI*	p	R^2	B	*95% CI*	p	R^2
Social structural characteristics								
Gender								
Female	0.168	−1.28 to 1.61	0.819		1.933	−0.18 to 4.05	0.073	0.024
Other	0.651	−2.71 to 4.01	0.703	0.001				
Relationship status	−0.992	−2.39 to 0.41	0.163	0.010	—	−3.02 to 0.86	0.273	0.009
With partner					1.081			
Age, years	0.021	−0.26 to 0.08	0.461	0.003	0.029	−0.04 to 0.09	0.401	0.007
Living arrangement		−2.39 to 0.76				−4.01 to 0.51	0.128	0.018
With partner, family, or others	−0.812		0.311	0.006	−1.750			
Autism severity								
Total AQ score	0.104	0.04–0.17	0.003**	0.045	0.195	0.13–0.26	<0.001***	0.228
Social behavior								
Social skill	0.446	0.27–0.62	<0.001***	0.113	0.562	0.41–0.71	<0.001***	0.311
Routine	1.475	0.18–2.77	0.026*	0.025	2.016	0.44–3.59	0.012*	0.047
Switching	1.482	0.18–2.78	0.025*	0.024	2.975	1.67–4.28	<0.001***	0.145
Imagination	0.931	−0.30 to 2.16	0.137	0.012	2.494	0.64–4.34	0.009**	0.059
Factor numbers and patterns	0.045	−0.17 to 0.26	0.682	0.001	0.281	0.02–0.54	0.034*	0.035
Employment status	−1.446	−2.86 to −0.03	0.045*	0.020	—	−3.15 to 1.05	0.325	0.009
Employed					1.049			
Characteristics of social network								
Frequency of contact with family	−0.742	−1.16 to −0.32	0.001**	0.058	−1.180	−1.84 to −0.52	0.001**	0.087
Frequency of contact with friends	−1.1520	−1.55 to −0.75	<0.001***	0.135	−1.591	−2.24 to −0.94	<0.001***	0.166
No. of support persons SSQN score	−1.238	−1.59 to −0.88	<0.001***	0.192	−1.107	−1.47 to −0.75	<0.001***	0.226
Cognitive appraisal of social network								
Satisfaction with support persons SSQS score	−2.106	−2.53 to −1.68	<0.001***	0.324	−3.542	−4.42 to −2.66	<0.001***	0.377
Personality characteristics								
Depression (PHQ-9)	0.301	0.21–0.39	<0.001***	0.174	0.453	0.28–0.63	<0.001***	0.180
Anxiety (DSM-5)	0.216	0.14–0.29	<0.001***	0.129	0.340	0.19–0.49	<0.001***	0.148
Self-efficacy (NGSE)	−1.291	−1.99 to −0.58	<0.001***	0.059	−1.756	−3.26 to −0.25	0.023*	0.039

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

and anxiety became nonsignificant. The model in the nonautistic group accounted for 58% of variance, with three significant associations with loneliness: AQ-short social skills ($B = 0.28$, $p = 0.003$), number of support persons ($B = -0.43$, $p = 0.009$), and dissatisfaction with social support ($B = -2.37$, $p < 0.001$).

Thematic analysis

Sixty-eight autistic participants commented about their socialization. After coding, three overarching themes emerged: (1) satisfaction and dissatisfaction in socialization, (2) interpreting socialization, and (3) barriers to and supports for socialization. Figure 3 illustrates the thematic map of findings.

Satisfaction and dissatisfaction in socialization. Participants expressed either dissatisfaction with their socialization, satisfaction in socialization, or satisfaction in aloneness. Those who were dissatisfied described unhappiness about being alone, or having few friends, little social interaction, or superficial relationships: ''I don't really socialise(…)as much as I'd like…I feel more isolated and alone than I do connected with the world,'' ''can't seem to have proper friendships.'' Participants who were satisfied with their socialization revealed the company of friends or family: ''I am pretty happy being reclusive and having the support of my husband and companionship of my daughter and mother sometimes.'' The desired frequency of contact, however, was variable: ''Physically seeing friends once or twice a week is…enough.'' ''… I like being with myself a lot,'' ''I'm alone but not lonely.'' These latter comments also demonstrate the participants' conceptual understanding of loneliness as a feeling or perception of social satisfaction rather than simply a lack of company.

Interpreting socialization. Respondents interpreted socialization, whether unnecessary, anxiety-provoking, traumatic, or positive. These feelings tended to be shaped by positive or negative past experiences. Some participants did not feel a need to socialize because ''it is not me,'' they had ''grown out of the need,'' or would prefer to avoid socialization for it was

TABLE 4. MULTIPLE REGRESSION ANALYSES TO PREDICT LONELINESS ON UCLA 8-ITEM LONELINESS SCALE IN AUTISTIC AND NONAUTISTIC GROUPS

	Autistic (n = *208*)			*Nonautistic* (n = *146*)		
	Adjusted $R^2 = 0.418$			*Adjusted* $R^2 = 0.585$		
	B	*95% CI*	p	B	*95% CI*	p
Social structural characteristics						
Gender						
Female	–0.893	–2.16 to 0.374	0.166	1.456	–0.12 to 3.03	0.070
Relationship status						
With partner	–1.390	–2.91 to 0.13	0.073	–0.542	–2.41 to 1.32	0.567
Age, years	–0.004	–0.14 to 0.89	0.889	0.012	–0.04 to 0.07	0.675
Living arrangement						
With partner, family or others	0.304	–1.39 to 2.00	0.723	–0.184	–2.44 to 2.07	0.871
Autism severity						
Social behavior						
Social skill	0.190	–0.08 to 0.39	0.060†	0.279	0.09 to 0.46	0.003**
Routine	–0.217	–1.46 to 1.03	0.732	–0.905	–2.35 to 0.54	0.216
Switching	0.862	–0.40 to 2.12	0.180	0.719	–0.71 to 2.15	0.319
Imagination	–0.358	–1.56 to 0.84	0.558	0.098	–1.39 to 1.58	0.896
Factor numbers and patterns	0.029	–0.15 to 0.21	0.755	0.135	–0.09 to 0.36	0.243
Employment status						
Employed	0.513	–0.65 to 1.68	0.386	0.554	–1.29 to 2.39	0.550
Characteristics of social network						
Frequency of contact with family	–0.199	–0.58 to 0.18	0.298	0.214	–0.43 to 0.86	0.512
Frequency of contact with friends	–0.379	–0.82 to 0.06	0.094	–0.336	–0.91 to 0.23	0.247
No. of support persons SSQN score	–0.288	–0.74 to 0.164	0.210	–0.430	–0.75 to –0.11	0.009**
Cognitive appraisal of social network						
Satisfaction with support persons SSQS score	–1.438	–1.96 to –0.91	<0.001***	–2.365	–3.25 to –1.48	<0.001***
Personality characteristics						
Depression (PHQ-9)	0.008	–0.14 to 0.16	0.913	0.035	–0.17 to 0.24	0.741
Anxiety (DSM-5)	0.120	–0.01 to 0.23	0.033*	0.118	–0.04 to 0.28	0.156
Self-efficacy (NGSE)	0.252	–0.48 to 0.99	0.499	–0.116	–1.33 to 1.11	0.851

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$, †$p < 0.05$ if nonbinary gender participants included.

perceived as burdensome: ''people are a necessary by-product of these activities (shopping, repairs)…I put on an act to get through the need to socialise.'' For some, social situations were even traumatic or anxiety provoking: ''I must live socially like a nomad, never staying for too long, always fearful of the angry mob,'' ''people have been so cruel to me, I don't socialise ever anymore.'' This highlights the devastating impact of bullying and negative experiences on desire for socialization: ''socialising has caused so much anxiety in the past that now I am happiest on my own doing my own

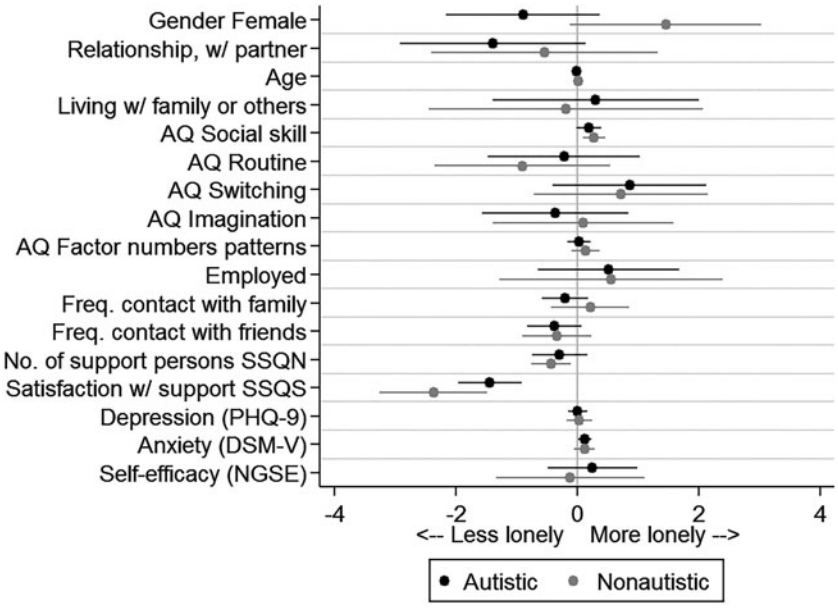

FIG. 2. Multiple regression analyses to predict loneliness on ULS-8 in autistic and nonautistic groups.

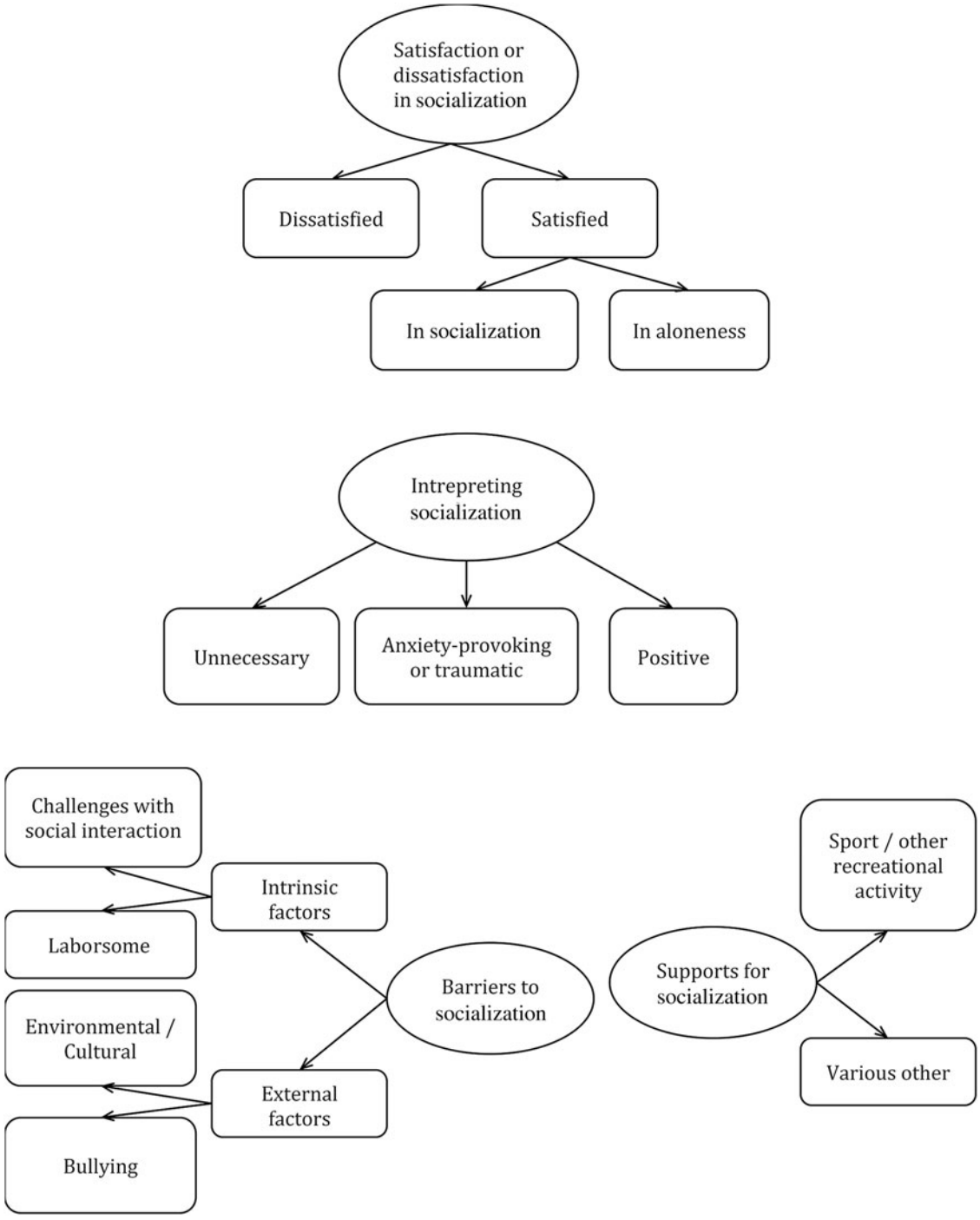

FIG. 3. Thematic map of themes emerging from qualitative data regarding socialization.

thing.'' In contrast, some participants demonstrated a positive view: ''…enjoy spending time with friends,'' ''…energised by interaction.''

Barriers to and supports for socialization. Finally, participants identified intrinsic and extrinsic barriers or supports to socialization. Many voiced their impressions on social skills such as initiating, understanding cues, or following conversations in large groups feeling ''isolated and withdrawn,'' ''disappear(ing) from peoples' attention easily.'' Some felt misunderstood: ''I think I come off to others as aloof when that's not how I am,'' ''they cannot ever understand what really goes on in my atypical mind.'' Others expressed understanding the use of conversational nuances such as discourse markers or visual and verbal cues, although these were perceived as ''nonsensical phrases,'' and potentially exhausting: ''draining to mentally prepare,'' ''I wish…that I could be around my friends more without being so tired afterwards.''

A prominent extrinsic barrier was bullying. Several participants described being bullied or excluded in both

social and work situations: ''I am basically IGNORED by almost everyone…I have to do all the attempts to start a conversation,'' ''not at work, there is inherent distrust now due to bullying… I go to do a job, walk at lunch, and then go home.'' Social upheaval in moving home, noisy environments, and not participating in drinking were also felt as disruptive of one's socialization and caused isolation. Conversely, a quiet setting was noted as a positive strategy for socialization, as was playing sport or other recreational activity: ''I play golf partly to motivate myself to socialise with others.''

Discussion

Consistent with earlier studies of autistic children and adolescents,[3,19] the present findings indicate that autistic adults are lonelier than nonautistic adults. Several common factors, including the AQ-short subdomain of social skill difficulty and dissatisfaction with social support, were associated with loneliness in both autistic adults and nonautistic adults. For autistic adults, female gender was protective while anxiety correlated with loneliness. For nonautistic adults in contrast, the number of support persons was significant. Autism-specific considerations have mainly emerged from the qualitative data.

Evaluation of social network characteristics and cognitive appraisal of social network has shown partial consistency with the model of loneliness. The varied perceptions of socialization demonstrate that there is significant association between dissatisfaction with social support and loneliness. Our results showed that the dissatisfaction with social support was more significant than the number of supports and contact frequency. Although the existing literature has found that greater quantity and quality of friendships are related to decreased loneliness in autistic adults,[31] our finding suggests that the perception of support is more important than objective quantification. Hence social supports for autistic adults should first and foremost address what each individual would appreciate as a support.

In the social structural characteristics domain of the model, female gender as a protective factor against loneliness in autistic adults is consistent with findings of higher friendship quality ratings found in autistic girls compared with boys.[32] Relationship status and living arrangement were not associated with loneliness in either nonautistic or autistic group, unlike previous studies in nonautistic populations that found that having no partner predicted loneliness.[33] Those studies, however, were limited by the majority of participants being widowed or divorced and the population of adolescents.[13,33] Perhaps the association between relationship status and loneliness in autistic adults can be further explored.

Our investigation also showed that the AQ-short subdomain of social skills was associated with loneliness, whereas social communication dissimilarities were highlighted in our thematic analysis. Autistic participants disclosed that they have had negative experiences including initiating conversation, being understood, and following cues. Some of our participants have attempted to adopt techniques of ''normal social etiquette.'' Although autism, currently defined by the DSM-5 criteria, includes difficulty in social interaction and communication, the despair and frustration communicated by our participants assert that these negative experiences do not restrict their desire for friendship nor minimize their relational needs. Notably, studies of social interaction in online gaming settings demonstrated that autistic individuals were as social as other participants and their interactions could be as complex and intimate.[34,35] The virtual environment may have attenuated the social barriers because a physical environment would have made social norms more apparent.

However, the assumption that definable social norms and rules should exist is challenged by the ''double empathy problem'' theory. In reference to a discrepancy in reciprocity between two differently disposed social actors, the theory explains that neurotypical individuals equally lack insight into autistic individuals; therefore, rather than defining autism as a social deficit, there ought to be understanding of differences in sociality.[37] The emergence of the neurodiversity movement may push for society's acceptance of difference, or rather toward an obligation of ''reciprocity and mutuality'' toward the valued minority in society.[36]

Moving on to the personality characteristics domain, anxiety was found to be associated with loneliness in autistic adults but not in nonautistic adults. Although anxiety was previously associated with loneliness in an autistic population, the direction of causality, if present, is unclear.[37] Anxiety is nonetheless understood as a comorbidity of loneliness.[1] We recorded significantly higher anxiety scores for the autistic adults. Conversely, anxiety may contribute to loneliness as social anxiety was shown to do so in a general population.[13] Descriptions of anxious thoughts about socialization by our autistic participants may be indicative of a relationship between social anxiety and loneliness. However, a specific study of social anxiety is necessary to clearly understand the association of social anxiety and loneliness in the autistic population, as well as the direction of causality.

Finally, the qualitative analysis in this study suggested marked interindividual variation in the impressions of loneliness among autistic adults. The variety of impressions ranged from satisfaction with socialization, dissatisfaction with lack of socialization to contentment in aloneness. Those in the latter group may score high on the ULS-8, for instance high score for item ''I lack companionship,'' but had not actually perceived themselves as lonely because they did not feel a need to socialize. Contrastingly, others had described having company or being in a crowd but lacking friendship. The comments demonstrate autistic adults' understanding of loneliness as a subjective concept; this evidence is noteworthy because inadequate understanding about loneliness and friendship was previously shown to cause more frequent and intense lonely experiences in autistic children.[4] Further investigation into the development of these perceptions from childhood into adulthood would facilitate our understanding of how loneliness impacts autistic adults. Other participants had expressed resignation to isolation or avoidance of social interaction consequent to negative past experiences such as bullying or social exclusion. This impact is consistent with literature identifying bullying as a determinant for minimized interest in socialization in autistic adults.[4,38–41] The findings support that negative perceptions as a result of victimization may evolve into avoidance or resignation of socialization.

Limitations and future directions

This study consisted of self-selected participants recruited though nonprobability sampling. Nonautistic participants may selectively have an interest in autism. A recruitment bias was evidenced in gender imbalance wherein the majority of both samples were females, but predominantly so in the nonautistic sample. Competent literacy skills were required to complete the self-report questionnaire and may thereby select a subgroup without intellectual disability. Nevertheless, external validity is strengthened by national recruitment and wide sampling frame.

The cross-sectional study design limits interpretation of direction of causality between variables and loneliness. Continuation of ALSAA into a longitudinal study will facilitate the observation of variables and their association with loneliness developing over time. Not all aspects of the investigative framework for loneliness such as introversion/extroversion and social anxiety could be analyzed as they were not included in the ALSAA Time 1 survey; however, Time 2 includes these measures.[42] Some measures such as the ULS-8 and NGSE have not been validated in the autistic population. This study suggests that some autistic adults have good conceptual understanding of loneliness, but further exploration is required to better understand how autistic adults experience loneliness.

Previous authors have reported differences in the nature of friendships on loneliness outcomes, whether best friend, friend with disability, or sibling.[13] Further study identifying these relationship types may help elucidate their effects on loneliness for autistic adults. Moreover, this study did not distinguish between autistic and nonautistic peers; it would be useful to explore how this difference may influence perception of social skills, and satisfaction in socialization in determining felt loneliness. Finally, thematic analysis was of a single broad feedback question. Structured qualitative data collection would better explore and qualify the themes.

Conclusion

Autistic adults experience greater loneliness than nonautistic adults. Dissatisfaction with social support and the AQ-short subdomain of social skills were associated with loneliness in both populations. For autistic adults, there was diversity of preferences for social interaction and supports, and of perceived barriers. This subjectivity of the loneliness phenomenon reinforces that improved social support must be informed by the specific needs of autistic individuals. Furthermore, dissimilarity in social interaction and communication as a barrier to socialization should prompt society toward reciprocity. Reciprocity will be difficult to develop if the society continues to perpetuate the present social norm. Nevertheless, acceptance of differences in social communication is an essential beginning.

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Authors' Contributions

This article is based on the original student project research of D.E., supervised by J.H., S.R., J.T., K.F., and S.A. D.E., J.H., S.R., J.T., K.F., and S.A. contributed to conceptualization and design, analysis and interpretation of research data, and drafting significant parts or critically revising the article. P.S. contributed to analysis and interpretation of research data and drafting significant parts or critically revising the article. All authors have reviewed and approved this article.

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