




RESEARCH ARTICLE

Continuity and change in loneliness and stress during the COVID-19 pandemic: A longitudinal study of autistic and non-autistic adults

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Abstract

Previous studies have suggested that autistic adults may be negatively affected by the COVID-19 pandemic and its associated restrictions. In this study, we examined continuity and change in loneliness and stress, and their predictors, in 448 autistic and 70 non-autistic adults living in the Netherlands. Autistic participants were assessed on three occasions using the de Jong Gierveld Loneliness Scale and Perceived Stress Scale (pre-lockdown (T0), first lockdown (T1), and second lockdown (T2)); non-autistic participants were assessed twice (T1 and T2). Autistic adults' loneliness and stress levels remained stable across all three time points over 8 months, but were consistently higher than those of non-autistic adults. Other predictors of higher loneliness and stress levels at the first lockdown (T1) included low perceived social support and high levels of COVID-19 related worries. Although loneliness and stress were stable at the group level, the wellbeing of some autistic adults worsened over the course of the pandemic, while others improved. For instance, adults with a mental health diagnosis (other than autism) prior to the pandemic were more likely to increase in stress over time, whereas adults with higher perceived social support were more likely to decrease in stress over time (from T1 to T2). Factors contributing to variability in outcome require further examination. Moreover, the relatively high loneliness and stress levels in autistic adults call for attention from clinicians and service providers.

Lay summary

In our study, autistic adults reported feeling more lonely and stressed than non-autistic adults during the COVID-19 pandemic. People who missed support from their social network also felt more lonely and stressed. On average, people did not change substantially in their degree of loneliness or stress over time. Yet, we noted large person-to-person differences in the wellbeing of autistic adults during the pandemic.

KEYWORDS

autism, adults, COVID-19, loneliness, stress, wellbeing

The COVID-19 pandemic and its associated restrictions—including travel bans, wearing face masks, working from home, and keeping physical distance from others—have had mixed effects on mental health, with some studies showing overall stability in mental health and loneliness (Ahrens et al., 2021; Luchetti et al., 2020;

O'Connor et al., 2020; Voltmer et al., 2021), while other studies suggest a deterioration in people's mental health and loneliness (Bu et al., 2020; Jia et al., 2020; Santamauro et al., 2021). For instance, Santamauro et al. (2021) reported a worldwide rise in rates of clinical depression (estimation of 53 million additional cases) and

anxiety disorders (estimation of 76 million additional cases) during the COVID-19 pandemic. Similarly, a meta-analysis of mental health data collected prior to and during the pandemic from 43 studies involving a total of 71,613 adults in different continents (mostly Asia and Europe) indicated a modest rise, overall, in anxiety symptoms and a moderate increase in depressive symptoms in the general population, but no concomitant changes in stress or sleeping problems (Kunzler et al., 2021). Female gender, young adulthood, living alone, unemployment, prior mental health issues, and COVID-19 related worries have all been identified as risk factors for poorer mental health and more loneliness during the pandemic (Benke et al., 2020; Groarke et al., 2020; Jia et al., 2020; Nikolaidis et al., 2021; O'Connor et al., 2020).

Autistic people may be disproportionately affected by the impact of the COVID-19 pandemic. First, continuous changes in government restrictions, including the (partial) lifting of these restrictions, may be particularly stressful for autistic individuals as many have difficulties coping with uncertainty, preferring structure, predictability, and routines (APA, 2013). Indeed, disruption of routines has been highlighted as one of the issues autistic people have struggled with most during the pandemic (Oomen et al., 2021; Pellicano et al., 2021). Second, autistic people have been at heightened risk of losing their access to essential resources, services and supports during the pandemic (Pellicano et al., 2021; White et al., 2021), potentially increasing emotional and behavioral difficulties (Mutluer, Doenvas, & Aslan, 2020; White et al., 2021). Finally, autistic adults may be at increased risk of poorer mental health during the pandemic, as they share several known risk factors including high rates of prior psychiatric conditions (Hollocks et al., 2019) and high unemployment rates (Roux et al., 2013). In sum, one would expect especially deleterious effects of the pandemic on the mental health of autistic adults due to difficulty with change, potential loss of services and support, and other known risk factors.

Consistent with this idea, several studies have identified risk factors for a poorer mental health of autistic adults during the COVID-19 pandemic (e.g., female gender, younger age, and presence of prior mental health conditions/symptoms) and reported a deterioration in their mental health (Adams et al., 2021; Bal et al., 2021; Oomen et al., 2021; Pellicano et al., 2021). These studies, however, were primarily based on retrospective reports of the impact of the pandemic and none included pre-pandemic assessments (although Adams et al., 2021 did include a pre-lockdown assessment). A possible deterioration in the mental health of autistic adults comes on top of already higher pre-pandemic levels of psychological distress (Bishop-Fitzpatrick et al., 2017; Hirvikoski & Blomqvist, 2015) and an increased risk of loneliness (Lin & Huang, 2019; Mazurek, 2014) compared to the general population. Nevertheless, two follow-up studies in the US have shown overall stable levels of

psychological distress (Bal et al., 2021; $n = 396$) and anxiety and depressive symptoms (Adams et al., 2021; $n = 275$) in autistic adults across a period of 2 months during the early phase of the COVID-19 pandemic. Further still, one UK-based study reported an overall decrease in anxiety and stress in 70 autistic adults from pre-lockdown to lockdown (across 10–15 weeks), although a minority showed a clinically significant increase in anxiety and stress (Bundy et al., 2022). Thus, the COVID-19 pandemic and its associated restrictions seem to have a negative effect on some, but may also entail benefits for others. Indeed, less crowded public spaces, keeping physical distance from others, and no commuting could reduce the risk of sensory overload (Oomen et al., 2021), a frequently reported problem for autistic people (MacLennan et al., 2021). Furthermore, a restriction on social gatherings may also lower stress through the reduction of social demands and pressures (Oomen et al., 2021). Yet, as Pellicano et al. (2021) point out in their qualitative study, many autistic adults missed their in-person social connections during the pandemic, which they felt had a negative impact on their mental health (see also Oomen et al., 2021).

This rather mixed set of findings might be attributable, at least in part, to methodological issues. For example, most studies to date examining the impact of the COVID-19 pandemic on autistic people's lives have either been cross-sectional (Oomen et al., 2021), lacked pre-pandemic or pre-lockdown measurements (Bal et al., 2021; Oomen et al., 2021), lacked a non-autistic comparison group (Adams et al., 2021; Bal et al., 2021; Bundy et al., 2022), and/or included a relatively small sample (Bundy et al., 2022). In the current study, we sought to address some of these issues by examining continuity and change in loneliness and stress during the COVID-19 pandemic, and their predictors, in autistic and non-autistic adults living in the Netherlands over a longer, 8-months period. We tested the possibility that the disadvantages of a lockdown, in terms of psychological distress and loneliness, would outweigh the benefits for most autistic adults. Utilizing data from the Netherlands Autism Register (NAR) cohort study (<https://www.nederlandsautismeregister.nl/english/>), we measured stress and loneliness in autistic adults (age ≥ 16 years) at three time-points: pre-lockdown (T0: March 2020), 6 weeks later during the first lockdown (T1: April 2020), and 6 months later during the second lockdown (T2: October 2020). At both lockdowns (T1 and T2), we also collected data on stress and loneliness in non-autistic adults. Drawing from the literature to date which we have critically summarized above, we hypothesized that:

(1a) stress and loneliness levels in autistic adults would increase from pre-lockdown (T0) to lockdown (T1 and T2) but

(1b) would remain stable across the 6-months period from the first (T1) to the second lockdown (T2) in both groups;

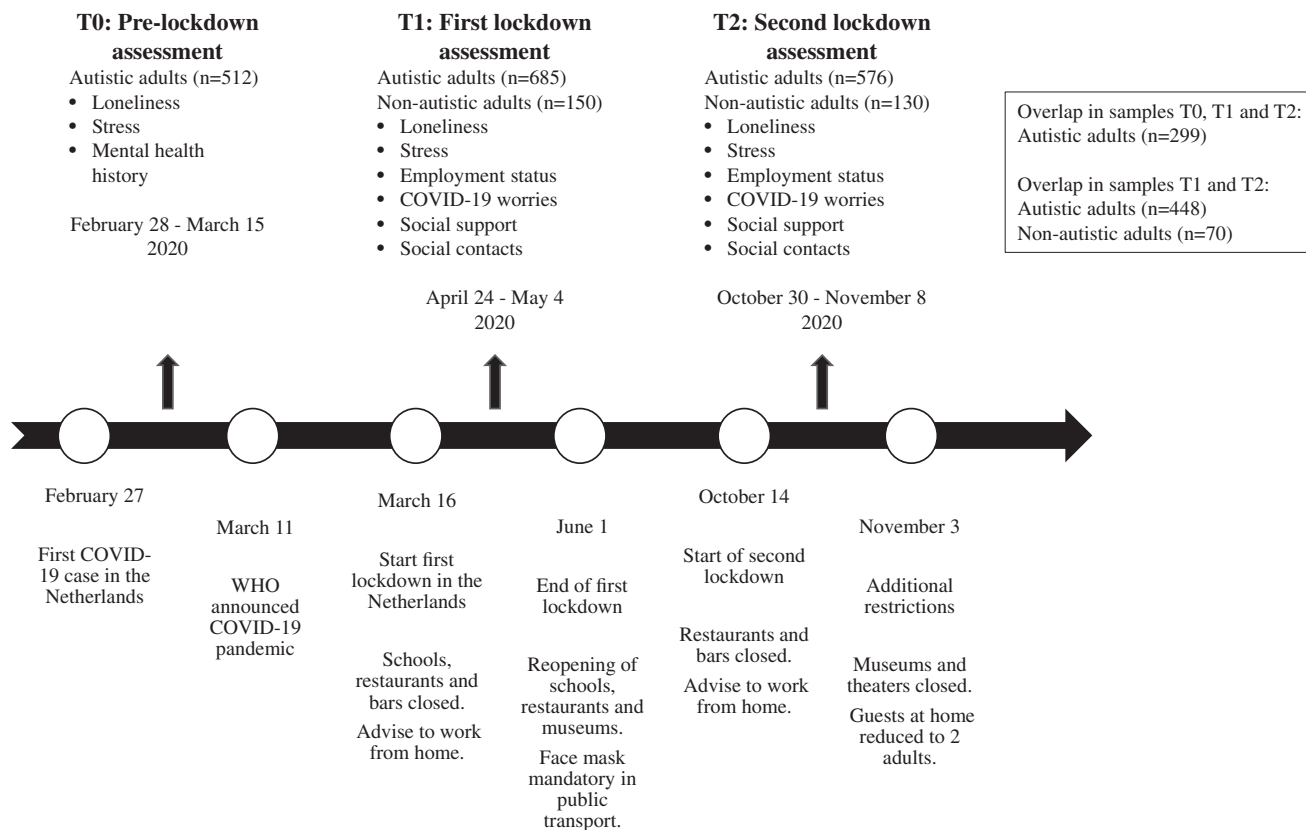


FIGURE 1 Study design and timeline of COVID-19 related restrictions in the Netherlands in 2020

(2) Autistic adults would report higher levels of loneliness and stress than non-autistic adults during lockdown (at T1 and T2); and

(3) the predictors of higher loneliness and stress levels (and their increases over time) would be similar in autistic and non-autistic adults and comparable to those identified in other studies to date, specifically: female gender, younger age, prior mental health diagnosis, unemployment, and lower social support during the pandemic, few social contacts in the past week, and more COVID-19 related worries.

METHOD

Study design

This study included three self-report assessments of autistic participants (T0, T1, and T2) and two assessments of non-autistic participants (T1 and T2). For an overview of the study design and COVID-19-related restrictions in the Netherlands in 2020, see Figure 1.

Participants

All data were from the Netherlands NAR, a database of autistic and non-autistic adults and parents of autistic individuals. Upon registration, autistic adults of the NAR confirm that they have a clinical diagnosis of autism spectrum

disorder (ASD) as established by an authorized professional (e.g., psychiatrist/psychologist). Non-autistic adults make up a comparison group. Exclusion criteria for non-autistic adults in the NAR are (1) an ASD diagnosis and (2) having a first-degree family member with autism.

In March 2020 (T0), before the first lockdown in the Netherlands, we collected loneliness and stress data from autistic adults as part of the standard annual online NAR survey. Six weeks later, in April 2020 (T1), 685 autistic adults (59% women; 55% with high educational level; 59% [$n = 406$] with T0 pre-lockdown data), between 16 and 85 years, participated in our COVID-19 study. At this point, we also collected data from 150 non-autistic adults from the NAR (75% women) to enable comparisons on key variables of interest (see Table 1 for sample characteristics). Six months later, in October 2020 (T2), 448 autistic (66% of the T1 sample) and 70 non-autistic adults (47% from T1) participated again (Table 2). In the Supplement, we report the statistical check of selective attrition of participants and data.

Measures

Outcome variables

Loneliness

We used the six-item version of the De Jong Gierveld Loneliness Scale (DG Loneliness Scale-6; De Jong

TABLE 1 Descriptive statistics (mean, *SD*, or *n*, %) of autistic and non-autistic adults during the first lockdown (T1) in the Netherlands

Variable	Autistic adults (<i>n</i> = 685)	Non-autistic adults (<i>n</i> = 150)	Group difference χ^2 / t -test (sig.)	Effect size (Cohen's <i>d</i> / phi / Cramer's <i>V</i>)
Gender			13.50 (0.001)	0.13
Men	272 (40%)	36 (24%)		
Women	406 (59%)	113 (75%)		
Other	7 (1%)	1 (1%)		
Age	45.87 (13.91)	45.17 (14.47)	−0.55 (0.58)	0.05
Autistic traits (autism-spectrum quotient)	84.12 (10.82)	53.19 (11.26)	−31.41 (<0.001)	2.84
Intellectual ability ^a			20.93 (<0.001)	0.16
IQ < 86	84 (13%)	0 (0%)		
IQ 86–115	125 (19%)	33 (22%)		
IQ > 115	455 (69%)	115 (78%)		
Prior mental health condition ^b			90.69 (<0.001)	−0.33
Yes	450 (66%)	35 (24%)		
No	235 (34%)	115 (77%)		
Had a COVID-19 infection			2.31 (0.51)	0.05
Yes	2 (0.3%)	1 (1%)		
Suspected	59 (9%)	13 (9%)		
No	501 (73%)	116 (77%)		
Unknown	123 (18%)	20 (13%)		
Paid employment			45.26 (<0.001)	−0.23
Yes	327 (48%)	117 (78%)		
No	358 (52%)	33 (22%)		
Perceived social support (1–5)	3.45 (1.21)	4.05 (0.96)	6.59 (<0.001)	0.55
Social contact (0–42)	19.18 (8.15)	21.88 (7.70)	3.72 (<0.001)	0.34
COVID-19 related worries (5–30)	17.48 (4.91)	16.76 (4.27)	−1.82 (0.07)	0.16

^aIQ level was self-reported. Specifically, 53% of the autistic adults based their self-reported IQ on a previous IQ test score (IQ assessment took place independent of the current study), 47% estimated their IQ themselves; 42% of the self-reported IQ data of the non-autistic adults was based on a prior IQ test score, 58% was self-estimated.

^bAn autism diagnosis is not counted as a prior mental health condition.

Gierveld & Van Tilburg, 2006), covering emotional and social loneliness (e.g., “There are enough people I feel close to”). Participants indicate the extent to which each of the statements applies to them, as they are lately, by choosing one of five options: “Yes!”, “Yes”, “More or less”, “No”, and “No!”. The emotional loneliness items receive an item score of 5 for a “Yes!” and 1 for a “No!”. The reverse applies to the social loneliness items. Total loneliness score varies between 6 and 30; higher scores indicate greater loneliness. Research has confirmed the scale's two-factor structure and adequate internal consistency (0.70 and 0.76; De Jong Gierveld & van Tilburg, 2006). The six-item version of the DG Loneliness Scale is highly correlated ($r's \geq 0.93$) with the original 11-item version (De Jong Gierveld & van Tilburg, 2006), and the scale content overlaps significantly with the UCLA Loneliness Scale (Russell, 1996). In the current study, Cronbach's alpha estimates were good to very good: 0.83 (T0), 0.81 (T1), and 0.81 (T2) for autistic adults, and 0.79 (T1) and 0.81 (T2) for non-autistic adults.

Perceived stress

We used the 10-item perceived stress scale (PSS-10; Cohen et al., 1983), a widely used self-report measure of perceived stress in the past month. Responses are rated on a 5-point Likert scale from “Never” (score of 0) to “Very often” (score of 4), yielding a total PSS score of 0 to 40. Higher scores indicate greater stress. An example item is: “In the last month, how often have you felt that you were unable to control the important things in your life?” The PSS-10 shows good internal consistency and positive correlations with other stress measures or related outcomes such as depressive symptoms and social anxiety (Cohen et al., 1983; Eskildsen et al., 2015; Ezzati et al., 2014). In the present study, Cronbach's alpha estimates were 0.88 (T0), 0.90 (T1), and 0.90 (T2) for autistic adults, and 0.89 (T1) and 0.90 (T2) for non-autistic adults.

Predictor variables

Participants were asked about their occupational status, perceived social support, amount of social contact, and

TABLE 2 Descriptive statistics (*n*, % or *M*, *SD*) of autistic and non-autistic adults with repeated measures of loneliness and stress at T0 (pre-lockdown), T1 (first lockdown), and T2 (second lockdown)

Variable	T0		T1		T2		T1 Group differences χ^2 / <i>t</i> -test (sig.)	T2 Group differences χ^2 / <i>t</i> -test (sig.)
	Autistic adults (<i>n</i> = 299)	Non-autistic adults (<i>n</i> = 70)	Autistic adults (<i>n</i> = 448)	Non-autistic adults (<i>n</i> = 70)	Autistic adults (<i>n</i> = 448)	Non-autistic adults (<i>n</i> = 70)		
Gender								
Men	126 (42%)	21 (30%)	193 (43%)	21 (30%)	193 (43%)	21 (30%)	4.34 (0.11)	
Women	170 (57%)	48 (69%)	251 (56%)	48 (69%)	251 (56%)	48 (69%)		
Other	3 (1%)	1 (1%)	4 (1%)	1 (1%)	4 (1%)	1 (1%)		
Age	45.09 (14.06)	49.03 (14.11)	46.56 (13.72)	49.03 (14.11)	46.56 (13.72)	49.03 (14.11)	1.40 (0.16)	
Autistic traits (autism-spectrum quotient)	84.40 (10.92)	52.56 (10.00)	84.39 (10.91)	52.56 (10.00)	84.39 (10.91)	52.56 (10.00)	-22.93 (<0.001)	
Intellectual ability							10.55 (<0.01)	
IQ < 86	37 (13%)	0 (0%)	55 (13%)	0 (0%)	55 (13%)	0 (0%)		
IQ 86–115	59 (20%)	13 (19%)	91 (21%)	13 (19%)	91 (21%)	13 (19%)		
IQ > 115	195 (67%)	56 (81%)	293 (67%)	56 (81%)	293 (67%)	56 (81%)		
Prior mental health condition ^a							47.01 (<0.001)	
Yes	202 (68%)	17 (24%)	301 (67%)	17 (24%)	301 (67%)	17 (24%)		
No	97 (32%)	53 (76%)	147 (33%)	53 (76%)	147 (33%)	53 (76%)		
Paid employment							13.20 (<0.001)	11.88 (0.001)
Yes		49 (70%)	209 (47%)	49 (70%)	209 (47%)	49 (70%)		48 (69%)
No		21 (30%)	239 (53%)	21 (30%)	239 (53%)	21 (30%)		22 (31%)
Perceived social support (1–5)	3.42 (1.24)	4.07 (0.97)	3.42 (1.24)	4.07 (0.97)	3.42 (1.24)	4.07 (0.97)	4.99 (<0.001)	5.17 (<0.001)
Social contact (0–42)	19.06 (8.20)	20.91 (7.49)	19.06 (8.20)	20.91 (7.49)	19.06 (8.20)	20.91 (7.49)	1.78 (0.08)	4.35 (<0.001)
COVID-19 related worries (5–30)	17.49 (5.00)	17.03 (4.47)	17.49 (5.00)	17.03 (4.47)	17.49 (5.00)	17.03 (4.47)	-0.72 (0.47)	-1.10 (0.28)
Loneliness (6–30)	16.36 (5.03)	13.67 (4.16)	16.65 (4.93)	13.67 (4.16)	16.65 (4.93)	13.67 (4.16)	-4.79 (<0.001)	-4.46 (<0.001)
Perceived stress (0–40)	19.60 (7.03)	13.87 (6.69)	19.13 (7.90)	13.87 (6.69)	19.13 (7.90)	13.87 (6.69)	-5.30 (<0.001)	-6.29 (<0.001)

Note: All participants have at least participated at T1 and T2.
^aAn ASD diagnosis is not counted as a prior mental health condition.

COVID-19 related concerns. Participants also expressed their opinion about COVID-19 related restrictions and consequences (Supplementary Table S1).

A prior diagnosis of a mental health condition was ascertained prior to lockdown by asking participants about their psychiatric history. Reports of a prior psychiatric diagnosis (other than autism in the autistic sample) were coded as 1 (“prior mental health condition”) or 0 (“no prior mental health condition reported”).

Employment status was assessed at T1 and T2 by asking participants whether they currently had paid work, either salaried or self-employed (yes = 1; no = 0), including part-time work.

Perceived social support was assessed at T1 and T2 with a single item: “I experience sufficient support from my social environment”. Responses were rated on a 5-point Likert scale, ranging from “totally agree” (score of 5) to “totally disagree” (score of 1). Scores of 4 or 5 indicate sufficient perceived social support.

Amount of isolation and social contact in the past week was assessed at T1 and T2 with six questions. On a scale from 0 to 7, participants indicated the number of days of the past week that they, for instance, had face-to-face contact with someone for ≥ 15 minutes (see Supplement for all items). Item scores were summed to a total score (0–42; higher scores indicate more social contact and less isolation).

COVID-19 related worries were measured at T1 and T2 using three items. The first item “How worried have you been about the COVID-19 crisis in recent weeks?” was rated on a 10-point scale (1 = “not worried” to 10 = “extremely worried”). Two items describing worries about “getting sick yourself” and “someone close to you getting sick” were each rated on a 5-point scale (1 = “never” to 5 “always or almost always”). Scores on the latter two items were multiplied by two (to create a rating out of 10) and were added to the first item score, yielding a maximum score of 30; higher scores indicate more COVID-19 related worries. Because a low number of items (3) reduces internal consistency, Cronbach’s alpha estimates were moderate: 0.66 (T1) and 0.64 (T2) for autistic adults, and 0.62 (T1) and 0.59 (T2) for non-autistic adults.

Procedure

All data were collected online via the NAR and all participants gave informed consent. Ethics approval for this study was granted by the ethics committee of the Vrije Universiteit Amsterdam (VCWE 2020-041R1). This study was preregistered at the Open Science Framework (<https://osf.io/d3st7>).

Data analysis

To test hypothesis 1a, we compared loneliness and stress scores across T0, T1, and T2 with a repeated-measures

analysis of variance (ANOVA) in autistic adults only. Second, we did a Bayesian mixed ANOVA (Jeffreys, 1961), with Group (autistic and non-autistic) as between-subject variable and Time (T1 and T2) as within-subject variable, to examine the evidence in favor of hypothesis 1b that loneliness and stress levels would be similar at T1 and T2 (i.e., Time has no effect). Counter to a classic frequentist approach, which either accepts or rejects the null hypothesis, a Bayesian analysis can weigh the evidence both for the null and the alternative hypothesis. A Bayes factor (BF) of 1 indicates no evidence, between 1 and 3 anecdotal evidence, between 3 and 10 moderate evidence, between 10 and 30 strong evidence, between 30 and 100 very strong evidence, and above 100 extreme evidence for one hypothesis over the other (recommended by Jeffreys, 1961). Where BF_{01} indicates evidence for the null hypothesis (i.e., Time has no effect) over the alternative hypothesis (i.e., Time has an effect), BF_{10} indicates evidence for the alternative hypothesis over the null hypothesis.

To test hypotheses 2 and 3, we carried out multiple hierarchical linear regression analyses to predict (i) loneliness and (ii) stress levels at the first lockdown (T1). Predictors at Step 1 were gender, age, prior mental health condition, employment status (T1), perceived social support (T1), social contacts (T1), and COVID-19 related worries (T1). Because gender contained three categories (men/women/other gender), two dummy variables were created: one comparing men and women and one comparing women and participants identifying as other gender. Although the number of participants indicating other gender was small ($n = 8$), all participants were included in the analyses. Group (autistic vs. non-autistic) was added in Step 2 to examine the unique explained variance of group membership over and above the variance explained by the other variables. All group \times predictor interactions were added in Step 3, to check whether associations between predictors and outcome were moderated by group membership.

Finally, to get a better understanding of who is more likely to change in loneliness or stress over time, we ran multiple regression analyses to examine (1) predictors of loneliness and stress of autistic adults at the first lockdown assessment (T1), while controlling for their T0 loneliness and stress levels, and (2) predictors of loneliness and stress of autistic and non-autistic adults at the second lockdown assessment (T2), while controlling for their T1 loneliness and stress levels. To predict change in loneliness/stress levels in our autistic participants from T0 to T1, we entered T0 loneliness/stress level in the first step of the regression followed by gender, age, prior mental health condition, and living circumstances (living alone vs. living with others) in the second step. For the prediction of change in loneliness/stress level in our autistic and non-autistic participants from T1 to T2, we first entered T1 loneliness/stress level in the regression model (Step 1), followed by gender, age, prior mental health condition, T1 employment status, T1 perceived social support, T1

social contacts, and T1 COVID-19 related worries (Step 2). At Step 3, group was added. At Step 4, all group \times predictor interactions were added.

To correct for multiple tests, p -values smaller than 0.0063 (0.05 / 8 significance tests = 0.0063) were deemed statistically significant.

RESULTS

Table 2 shows descriptive statistics for all variables across time points and groups. Both at T1 and T2, the group of autistic adults reported significantly more loneliness and more stress than the non-autistic comparison group (Cohen's d s range from 0.65 to 0.81, indicating medium to large effect sizes). To better interpret the average loneliness scores of both samples, we compared these to existing norms (De Jong Gierveld & Van Tilburg, 2006). Based on these, 31% of the autistic adults were very lonely, 43% somewhat lonely, and 25% not lonely at T0. At T1, 33% of autistic adults felt very lonely (as compared to 11% of non-autistic adults), 45% somewhat lonely (non-autistic: 45%), and 22% not lonely (non-autistic: 44%). Similarly, at T2, 34% of autistic adults felt very lonely (non-autistic: 13%), 44% somewhat lonely (non-autistic: 45%), and 22% not lonely (non-autistic: 46%). No official norms exist for the PSS-10, our stress measure, as it was not developed for diagnostic purposes.

Change in loneliness and stress in autistic adults from pre-lockdown (T0) to lockdowns (T1 and T2) (hypothesis 1a)

Loneliness

A repeated-measures ANOVA was performed on loneliness scores with Time (T0, T1, and T2) as within-subject variable. Counter to our prediction, there was no significant effect of Time on autistic adults' loneliness levels, $F(2, 596) = 0.77$, $p = 0.46$, and $\eta_p^2 = 0.003$.

In line with this, an additional Bayesian repeated-measures ANOVA demonstrated very strong evidence in favor of the hypothesis that Time had no effect on loneliness, with a Bayes factor (BF_1) of 35.45, indicating that the observed data were 35.45 times more likely to occur if Time had no effect on loneliness levels (null model) compared to the alternative hypothesis that Time had an effect on loneliness.

Stress

A repeated-measures ANOVA on stress scores also indicated no effect of Time, $F(2, 606) = 0.87$, $p = 0.42$, and $\eta_p^2 = 0.003$. This result was confirmed by a Bayesian repeated-measures ANOVA, with a Bayes factor (BF_1) of 34.24, indicating that the observed data were 34.24

times more likely to occur if Time had no effect on stress (null model) compared to the alternative hypothesis that Time had an effect on stress.

Together, these findings demonstrate that loneliness and stress levels remained overall stable in this cohort of autistic adults from pre-lockdown (T0) to lockdown (T1 and T2; see Figure 2), although individual differences were also observed.

Stability in loneliness and stress in autistic and non-autistic adults from first (T1) to second (T2) lockdown (hypothesis 1b)

Loneliness

The Bayesian mixed ANOVA demonstrated moderate evidence in favor of our hypothesis (1b) that Time had no effect on loneliness from T1 to T2, with a Bayes factor (BF_1) of 9.65, indicating that the observed data were 9.65 times more likely to occur if Time had no effect on loneliness levels (null model) compared to the alternative hypothesis that Time had an effect on loneliness. Thus, moderate evidence was found for stable loneliness levels from the first to the second lockdown 6 months later. Other results of the Bayesian mixed ANOVA can be found in supplementary Table S2.

Stress

Moderate evidence ($BF_1 = 7.12$) was found in favor of the hypothesis that Time had no effect on stress at T1 and T2. The observed stress data were 7.12 times more likely to occur if Time had no effect on stress levels (null model) compared to the alternative hypothesis that Time had an effect. Hence, moderate evidence was found to support the hypothesis that, overall, participants' stress levels remained stable from first to second lockdown. Other results of the Bayesian mixed ANOVA can be found in supplementary Table S3.

Summing up, at the group level, loneliness and stress levels were stable from T1 to T2 in both groups. At the individual level, there was large variability in change over time.

Predictors of loneliness and stress at the first lockdown (T1; hypotheses 2 & 3)

Correlations between predictor and outcome variables can be found in supplementary Table S4.

Loneliness

The first step of the multiple regression model including all predictors, except group and the interaction terms,

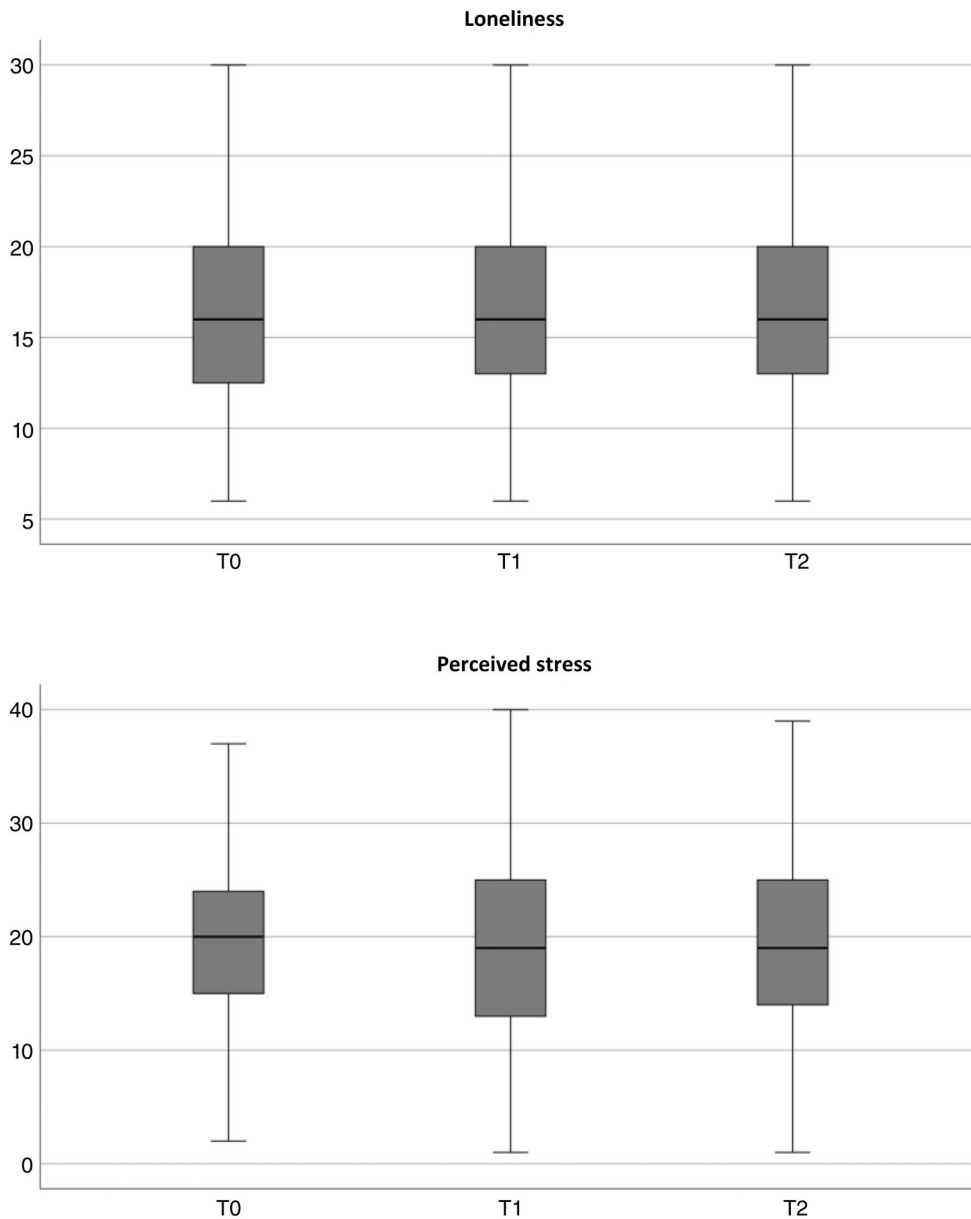


FIGURE 2 Loneliness and stress levels at T0 (pre-lockdown), T1 (first lockdown), and T2 (second lockdown) of autistic adults during the COVID-19 pandemic

explained 38% of variance in T1 loneliness ($F[8, 823] = 64.18, p < 0.001$; Table 3). As expected, adults with more perceived social support and those with fewer COVID-19 related worries at T1 reported significantly lower T1 loneliness. Age, gender, a prior mental health condition, employment status, and amount of social contact in the past week were not significant independent predictors of T1 loneliness ($p_s > 0.0063$). Adding group (autistic / non-autistic) at the second step significantly increased the amount of explained variance in loneliness, but only by 1% to 39% (F change $[1, 822] = 10.33, p = 0.001$). After controlling for all other predictors, and consistent with our hypothesis, autistic adults reported higher loneliness levels at T1 compared to non-autistic adults. The interaction terms in Step 3 did not add significant variance to the model, meaning that predictors for loneliness were similar for both groups.

Stress

The first step of the multiple regression model including all predictors, except group and the interaction terms, explained 23% of the variance in self-reported T1 stress ($F[8, 823] = 31.06, p < 0.001$). As hypothesized, older adults, those without a prior mental health condition, those with more perceived social support and those with fewer COVID-19 related worries reported lower T1 stress levels (Table 4). Gender, employment status, and amount of social contact in the past week were not significant independent predictors of T1 stress ($p_s > 0.0063$). Adding group to the regression model (Step 2) significantly increased explained variance in stress by 3% to 26% (F change $[1, 822] = 33.10, p < 0.001$), but having a prior mental health condition was no longer a significant predictor. As expected, autistic adults reported more stress

TABLE 3 Multiple regression model predicting levels of self-reported loneliness at T1 in autistic and non-autistic adults ($N = 832$)

Model	ΔR^2	B	SE	β	t	p	LB (CI)	HB (CI)
Model 1	0.38							
Gender (men vs. women)		0.126	0.299	0.012	0.422	0.673	-0.460	0.713
Gender (other vs. women)		2.163	1.505	0.040	1.437	0.151	-0.791	5.116
Age		-0.004	0.010	-0.011	-0.369	0.712	-0.024	0.016
T1 Employment		-0.570	0.287	-0.057	-1.987	0.047	-1.133	-0.007
Prior mental health condition		0.504	0.289	0.050	1.746	0.081	-0.063	1.071
T1 Social support		-2.408	0.119	-0.576	-20.285	<0.001	-2.641	-2.175
T1 Social contacts		-0.002	0.018	-0.002	-0.086	0.932	-0.036	0.033
T1 COVID-19 related worries		0.136	0.029	0.132	4.719	<0.001	0.080	0.193
Model 2	0.01							
Gender (men vs. women)		-0.046	0.302	-0.004	-0.151	0.880	-0.638	0.547
Gender (other vs. women)		2.186	1.496	0.040	1.461	0.144	-0.751	5.124
Age		-0.003	0.010	-0.007	-0.257	0.797	-0.023	0.017
T1 Employment		-0.422	0.289	-0.042	-1.462	0.144	-0.990	0.145
Prior mental health condition		0.215	0.301	0.021	0.716	0.474	-0.375	0.806
T1 Social support		-2.359	0.119	-0.565	-19.823	<0.001	-2.593	-2.126
T1 Social contacts		0.001	0.017	0.001	0.050	0.960	-0.033	0.035
T1 COVID-19 related worries		0.134	0.029	0.129	4.660	<0.001	0.078	0.190
Group (autism vs. comparison)		1.256	0.391	0.097	3.215	0.001	0.489	2.022

Note: Model 3 (including interaction terms) did not add explained variance over and above model 2. Significant p -values ($p < 0.006$) are in bold.

Abbreviations: HB (CI), higher bound of 95% confidence interval; LB (CI), lower bound of 95% confidence interval.

TABLE 4 Multiple regression model predicting level of experienced stress at T1 in autistic and non-autistic adults ($N = 832$)

Model	ΔR^2	B	SE	β	t	p	LB (CI)	HB (CI)
Model 1	0.23							
Gender (men vs. women)		-0.689	0.519	-0.043	-1.329	0.184	-1.708	0.329
Gender (other vs. women)		2.181	2.612	0.026	0.835	0.404	-2.946	7.308
Age		-0.094	0.018	-0.169	-5.241	<0.001	-0.129	-0.059
T1 Employment		-1.265	0.498	-0.082	-2.540	0.011	-2.243	-0.287
Prior mental health condition		1.704	0.501	0.109	3.401	0.001	0.720	2.687
T1 Social support		-1.669	0.206	-0.257	-8.101	<0.001	-2.074	-1.265
T1 Social contacts		0.017	0.030	0.018	0.570	0.569	-0.042	0.077
T1 COVID-19 related worries		0.493	0.050	0.306	9.823	<0.001	0.394	0.591
Model 2	0.03							
Gender (men vs. women)		-1.216	0.517	-0.076	-2.351	0.019	-2.231	-0.201
Gender (other vs. women)		2.254	2.563	0.027	0.879	0.379	-2.777	7.284
Age		-0.090	0.018	-0.163	-5.135	<0.001	-0.125	-0.056
T1 Employment		-0.813	0.495	-0.052	-1.642	0.101	-1.784	0.159
Prior mental health condition		0.819	0.515	0.052	1.589	0.112	-0.192	1.830
T1 Social support		-1.520	0.204	-0.234	-7.456	<0.001	-1.920	-1.120
T1 Social contacts		0.025	0.030	0.026	0.824	0.410	-0.034	0.083
T1 COVID-19 related worries		0.486	0.049	0.301	9.858	<0.001	0.389	0.582
Group (autism vs. comparison)		3.849	0.669	0.191	5.753	<0.001	2.536	5.162

Note: Model 3 (including interaction terms) did not add explained variance over and above model 2. Significant p -values ($p < 0.006$) are in bold.

Abbreviations: HB (CI), higher bound of 95% confidence interval; LB (CI), lower bound of 95% confidence interval.

TABLE 5 Multiple regression model predicting T2 loneliness, controlling for T1 loneliness, in autistic and non-autistic adults ($N = 518$)

Model	ΔR^2	B	SE	β	t	p	LB (CI)	HB (CI)
Model 1	0.53							
T1 loneliness		0.749	0.031	0.729	24.216	<0.001	0.688	0.809
Model 2	0.01							
T1 loneliness		0.710	0.040	0.691	17.651	<0.001	0.631	0.789
Gender (men vs. women)		0.254	0.329	0.025	0.773	0.440	-0.392	0.900
Gender (other vs. women)		-1.558	1.574	-0.030	-0.990	0.323	-4.651	1.535
Age		-0.013	0.012	-0.036	-1.120	0.263	-0.036	0.010
T1 employment status		-0.663	0.319	-0.066	-2.076	0.038	-1.291	-0.036
Prior mental health condition		0.086	0.327	0.008	0.263	0.793	-0.556	0.728
T1 social support		-0.197	0.161	-0.048	-1.222	0.222	-0.513	0.120
T1 social contacts		-0.001	0.020	-0.001	-0.035	0.972	-0.039	0.038
T1 COVID-19 related worries		-0.013	0.032	-0.013	-0.409	0.682	-0.076	0.050
Model 3	0.01							
T1 loneliness		0.700	0.040	0.682	17.418	<0.001	0.621	0.779
Gender (men vs. women)		0.123	0.332	0.012	0.371	0.711	-0.529	0.776
Gender (other vs. women)		-1.455	1.568	-0.028	-0.928	0.354	-4.535	1.626
Age		-0.010	0.012	-0.028	-0.878	0.380	-0.034	0.013
T1 employment status		-0.592	0.319	-0.058	-1.852	0.065	-1.219	0.036
Prior mental health condition		-0.133	0.338	-0.013	-0.392	0.695	-0.797	0.532
T1 social support		-0.177	0.161	-0.043	-1.102	0.271	-0.492	0.138
T1 social contacts		0.000	0.020	-0.001	-0.016	0.987	-0.039	0.038
T1 COVID-19 related worries		-0.014	0.032	-0.013	-0.426	0.671	-0.076	0.049
Group (autism vs. comparison)		1.135	0.482	0.077	2.352	0.019	0.187	2.083

Note: Model 4 (including interaction terms) did not add explained variance over and above model 3. Significant p -values ($p < 0.006$) are in bold. Abbreviations: HB (CI), higher bound of 95% confidence interval; LB (CI), lower bound of 95% confidence interval.

than non-autistic adults. Group was not a moderating factor (Step 3), indicating that the predictors for stress at T1 were comparable across groups.

Predictors of change in loneliness and stress from pre-lockdown (T0) to first (T1) lockdown in autistic participants (hypothesis 3)

Loneliness

T0 loneliness was a significant predictor of T1 loneliness in autistic adults, explaining 47% of the variance ($F[1, 368] = 3331.94, p = <0.001$; see supplementary - Table S5). None of the other predictors (gender, age, prior mental health condition, and living circumstances) was a significant independent predictor of T1 loneliness when T0 loneliness was accounted for (all $p_s \geq 0.09$).

Stress

Similarly, T0 stress level predicted T1 stress level in autistic adults ($F[1, 373] = 201.99, p = <0.001$; see

supplementary Table S6), explaining a total of 35% of the variance, but there were no other significant predictors of T1 stress ($p_s \geq 0.01$).

Predictors of change in loneliness and stress from first (T1) to second (T2) lockdown in autistic and non-autistic participants (hypothesis 3)

Loneliness

The regression model predicting T2 loneliness scores based on T1 loneliness scores explained 53% of the variance ($F[1, 516] = 586.41, p < 0.001$; Table 5). Variables added at Step 2, Step 3 (group), and Step 4 (interaction terms) did not significantly contribute to explained variance in T2 loneliness over and above the variance explained by T1 loneliness. Hence, consistent with the results from the repeated-measures ANOVA, autistic and non-autistic adults did not differ significantly in their change in loneliness between T1 and T2 when key variables were controlled for. Furthermore, the interaction terms (Step 4) did not explain additional variance, indicating that autistic and non-autistic adults had similar predictors of change in loneliness.

TABLE 6 Multiple regression model predicting T2 perceived stress, controlling for T1 perceived stress, in autistic and non-autistic adults ($N = 518$)

Model	ΔR^2	B	SE	β	t	p	LB (CI)	HB (CI)
Model 1	0.44							
T1 perceived stress		0.658	0.033	0.664	20.222	<0.001	0.594	0.721
Model 2	0.04							
T1 perceived stress		0.562	0.036	0.568	15.531	<0.001	0.491	0.633
Gender (men vs. women)		-0.359	0.542	-0.023	-0.663	0.508	-1.424	0.706
Gender (other vs. women)		1.616	2.601	0.020	0.621	0.535	-3.494	6.726
Age		-0.045	0.020	-0.080	-2.272	0.023	-0.085	-0.006
T1 employment status		-0.600	0.528	-0.038	-1.136	0.256	-1.637	0.437
Prior mental health condition		1.683	0.540	0.104	3.117	0.002	0.622	2.743
T1 social support		-0.693	0.223	-0.108	-3.114	0.002	-1.130	-0.256
T1 social contacts		0.062	0.032	0.064	1.912	0.056	-0.002	0.126
T1 COVID-19 related worries		0.140	0.055	0.088	2.545	0.011	0.032	0.247
Model 3	0.01							
T1 perceived stress		0.548	0.036	0.554	15.078	<0.001	0.477	0.620
Gender (men vs. women)		-0.615	0.547	-0.039	-1.124	0.261	-1.690	0.460
Gender (other vs. women)		1.836	2.587	0.023	0.710	0.478	-3.247	6.918
Age		-0.042	0.020	-0.073	-2.089	0.037	-0.081	-0.002
T1 employment status		-0.473	0.527	-0.030	-0.898	0.370	-1.508	0.562
Prior mental health condition		1.285	0.557	0.080	2.309	0.021	0.192	2.379
T1 social support		-0.637	0.222	-0.099	-2.868	0.004	-1.074	-0.201
T1 social contacts		0.064	0.032	0.066	1.970	0.049	0.000	0.127
T1 COVID-19 related worries		0.144	0.055	0.090	2.638	0.009	0.037	0.251
Group (autism vs. comparison)		2.130	0.796	0.093	2.676	0.008	0.566	3.693

Note: Model 4 (including interaction terms) did not add explained variance over and above model 3. Significant p -values ($p < 0.006$) are in bold. Abbreviations: HB (CI), higher bound of 95% confidence interval; LB (CI), lower bound of 95% confidence interval.

Stress

The first step of the multiple regression model, including T1 stress level, explained 44% of the variance in T2 stress level ($F[1, 519] = 408.93, p = <0.001$). Step 2 added 4% of explained variance in T2 stress level ($\Delta F[1, 519] = 4.67, p = <0.001$). As shown in Table 6, adults with a prior mental health diagnosis were more likely to increase in stress over time, whereas those with higher social support at T1 were more likely to decrease in stress over time. No other variables were significant independent predictors. As shown in Step 3, where group membership was added as a predictor, autistic and non-autistic adults did not differ in their change in stress level over the 6-months period between the two lockdowns. Furthermore, group did not moderate the association between the other predictors and change in stress (Step 4), indicating that autistic and non-autistic adults had similar predictors of change in stress from T1 to T2.

DISCUSSION

To our knowledge, this is one of the first studies to investigate continuity and change in loneliness and stress in

both autistic and non-autistic adults during the early stages of the COVID-19 pandemic. First, in these Dutch samples, we showed that, counter to our hypothesis (1a), autistic adults' loneliness and stress levels did not increase significantly from pre-lockdown (T0) to lockdown (T1 and T2). Second, as predicted (hypothesis 1b), both autistic and non-autistic adults showed overall stability in loneliness and stress levels from the first (T1) to second lockdown (T2) 6 months later. Third, autistic adults reported substantially more loneliness and stress than non-autistic adults at the two-lockdown assessments (T1 and T2), confirming hypothesis 2. Finally, both groups shared similar predictors of higher (or increases in) loneliness and stress levels (hypothesis 3), including a perceived lack of social support and a higher level of COVID-19 related worries.

Overall stability in autistic adults' stress and loneliness levels before and at the first lockdown

The overall stability in loneliness and stress in autistic adults from pre-lockdown to first lockdown 6 weeks later was unexpected, given that some previous studies indicated a deterioration in the mental health of autistic

adults during the COVID-19 pandemic (Adams et al., 2021; Oomen et al., 2021; Pellicano et al., 2021). However, methodological differences between these studies and ours may explain the different findings. Specifically, a retrospective method to measure change in mental health before and during the pandemic may have contributed to finding an overall deterioration in mental health in prior studies. For instance, when Bundy et al. (2022) asked 70 autistic adults how the pandemic had changed their mental health, a majority reported a worsening of mental health. However, when Bundy et al. (2022) relied on prospective standardized measures, they found an overall decrease in anxiety and stress levels of autistic adults across a period of 10–15 weeks (from pre-lockdown to lockdown). In the present study, the equally high levels of loneliness and stress before and at the first lockdown could mean that the lockdown had both negative as well as positive effects on the mental health of our autistic participants. Indeed, some qualitative studies have indicated mixed effects of COVID-19 related restrictions on autistic adults, reporting both a (temporary) relief of social obligations as well as a (gradually increasing) need for more face-to-face contact (Oomen et al., 2021; Pellicano et al., 2021). Alternatively, it may be that the loneliness and stress levels of our autistic participants were already high prior to the pandemic and lockdowns (c.f. Hirvikoski & Blomqvist, 2015; Lin & Huang, 2019), leaving little or less room for an increase. Also, stress may already have built up in the weeks just before lockdown after the first case of COVID-19 in the Netherlands was reported (see Figure 1).

Another possible explanation for the autistic group's stable loneliness and stress levels before and at the first lockdown is that the 6-weeks period was too short to detect meaningful change. Yet, our stress and loneliness measures were specifically designed to assess recent experiences, so these should be sensitive to changes across a relatively short period. Indeed, at an individual level, there was evidence of sensitivity to change, with some autistic participants showing a small-to-large increase in loneliness and stress from pre-lockdown to lockdown, while others decreased in loneliness and stress. This suggests that a lockdown, including social isolation, reduced commuting, online (rather than face-to-face) therapy, and keeping physical distance from others, can have positive effects on some autistic adults, but negative effects on others. As age, gender, having a prior mental health diagnosis, or living alone did not predict a change in loneliness or stress from pre-lockdown to lockdown, it remains uncertain who is most sensitive to the detrimental effects of a lockdown. Clues may be found in the regression analyses predicting change from the first to second lockdown. Adults with a prior mental health diagnosis were more likely to increase in their stress level over the 6-months period, implying that this group was more severely affected by the negative impact of the pandemic and its restrictions. Also, adults who experienced

sufficient social support during the first lockdown were more likely to report reductions in stress over the course of 6 months, suggesting that the quality of people's social networks and the support they receive from these social contacts may buffer against a buildup of stress.

Overall stability in loneliness and stress in both autistic and non-autistic adults at the first and second lockdown

As expected, loneliness and stress levels of both autistic and non-autistic adults were comparable at the first lockdown and the second lockdown 6 months later. This finding echoes earlier reports of stable levels of psychological distress, anxiety and depression in autistic adults across a 2 months period at the start of the pandemic (Adams et al., 2021; Bal et al., 2021), and several reports of stable stress and loneliness in the general population (Kunzler et al., 2021; Luchetti et al., 2020). In our study, the two lockdown assessments (T1 and T2) took place in a comparable context in terms of COVID-19-related restrictions in the Netherlands (see Figure 1), possibly contributing to similar loneliness and stress levels.

Group differences between autistic and non-autistic adults' stress and loneliness at lockdown

Autistic adults consistently reported more loneliness and stress than non-autistic adults during the pandemic (group differences indicated medium to large effect sizes). Even after statistically controlling for other risk factors wherein the groups differed (e.g., having a prior mental health diagnosis), group status explained additional variance over and above the other predictors. These results are concerning, as loneliness and stress are known risk factors for poorer physical and mental health (Leigh-Hunt et al., 2017; Luanaigh & Lawlor, 2008). One out of three autistic adults in our study reported severe loneliness compared to one in ten non-autistic adults (the latter resembling pre-pandemic loneliness ratings of the Dutch general population; Statistics Netherlands, 2020), suggesting that a substantial proportion of autistic adults has unmet social needs. This also corresponds with pre-pandemic reports of higher loneliness ratings among autistic adults (Lin & Huang, 2019). Creating opportunities to meet like-minded people (e.g., based on similar interests) and offering practical tools on how to make and maintain social connections may be potential ways to reduce loneliness. A recent meta-analysis also reported positive effects of psychological interventions on feelings of loneliness of varying groups of people (Hickin et al., 2021), including young adults with autism (Gantman et al., 2012). Our stress findings imply that daily life during lockdown was experienced as more stressful by autistic adults. Part of this elevated stress

may be due to difficulties dealing with uncertainty and changes in daily routines (APA, 2013; Oomen et al., 2021). Other previously identified stressors such as stigmatization and loss of (usual) therapy (Botha et al., 2020; Pellicano et al., 2021) were not measured in our study, but could play a role as well. It is noteworthy that average stress levels of our autistic ($M = 19.13/19.57$) and non-autistic participants ($M = 13.87/13.44$), as measured with the PSS-10, were roughly similar to pre-pandemic stress levels of autistic ($M = 19.45$) and non-autistic adults ($M = 11.40$) as reported by Bishop-Fitzpatrick et al. (2017). This tentatively suggests that group differences in stress might be similar in pandemic and non-pandemic times. Cognitive behavioral therapy or mindfulness based stress reduction may help to reduce psychological distress in autistic adults (Sizoo & Kuiper, 2017).

Predictors of pandemic loneliness and stress levels in autistic and non-autistic participants

Consistent with existing literature (Kunzler et al., 2021; Pellicano et al., 2021), less perceived social support at T1 predicted more stress and loneliness at T1, underlining the potential protective role of social support. In contrast, more COVID-19 related concerns were associated with more stress and loneliness. COVID-19-related worries, stress and loneliness may all be related to a broader construct, such as a general predisposition to experiencing anxiety and low mood. There may also be a causal link whereby worries about infection may lead to reduced social contacts, which in turn, lead to more unmet social needs. However, although our study was not designed to test for causal inferences, we found no association between frequency of social contacts and feelings of loneliness and it may thus be the quality (i.e., perceived social support) rather than the quantity of social contacts that affects loneliness.

Younger autistic and non-autistic adults reported more stress at the first lockdown. Plausibly, young adults were affected more by the sudden shift to studying/working from home and reduced social interactions with peers. As psychological stress is known to shorten the life span (Nielsen, Kristensen, Schnohr, & Grønbaek, 2008), an alternative methodological explanation could be selective attrition of individuals with higher stress levels with increasing age. Counter to previous general population research (Bu et al., 2020; Groarke et al., 2020), in this study younger (autistic and non-autistic) adults reported loneliness levels similar to those of older adults at the first lockdown. Further research is needed to examine the impact of social isolation on loneliness in autistic adults of different ages.

Contrary to previous research (Adams et al., 2021; Benke et al., 2020), women and unemployed adults did not report higher levels of loneliness and stress at the first

lockdown compared to men and employed adults (after applying a rather conservative Bonferroni correction). A stronger negative effect of the COVID-19 pandemic on women was expected in part due to the association of female gender with other variables such as being the primary caregiver, lower income, higher job insecurity, and a higher likelihood of being a victim of domestic violence (Santamauro et al., 2021). It is possible that the women and men in the present study did not substantially differ in these background variables, although that remains speculation for now.

With regards to employment status, employed and unemployed adults reported similar loneliness and stress levels. Daily life may have changed more radically for employed adults, as many were instructed to work from home. These changes may have been disruptive for some (e.g., work-life imbalance), leading to similar loneliness and stress levels as those of unemployed adults.

Adults with a prior mental health condition were not only more likely to increase in their stress over time, but also reported higher stress levels at the first lockdown, corresponding with previous findings (Bal et al., 2021; Kunzler et al., 2021). The effect of a prior mental health condition on T1 stress level disappeared once group status (autism) was added into the regression model. This is not surprising, as 66% of the autistic adults compared to only 24% of the non-autistic adults reported to have (had) a prior mental health condition. It therefore remains plausible that co-occurring mental health conditions (e.g., affective disorders) put people at increased risk of experiencing higher stress levels during the pandemic.

Strengths and limitations

Our study findings make an important contribution to the literature, as we were able to conduct repeated measures of loneliness and stress in both autistic and non-autistic adults during the early months of the COVID-19 pandemic, including a pre-lockdown assessment in a relatively large group of autistic adults, using a novel combination of both frequentist and Bayesian analyses. Nevertheless, this study also has several limitations. First, although we measured stress and loneliness of autistic adults before lockdown, the COVID-19 outbreak had already begun to spread globally by that time. Therefore, our autistic participants may already have experienced increased levels of stress and loneliness at the pre-lockdown assessment. Second, because we lacked pre-lockdown measurements in the non-autistic group, we were unable to examine changes in their stress and loneliness levels from pre-lockdown to lockdown. Third, although our study was inclusive of all genders, there were few adults who identified as 'other gender', limiting statistical power to detect an effect. Similarly, only few adults lost or gained (paid) employment between

lockdowns (see Supplementary Table S7). Finally, because autistic women, those with an adulthood autism diagnosis and those with a high educational level are overrepresented among self-reporting participants of the NAR, it is unclear whether the conclusions of this study are applicable to autistic groups with a childhood diagnosis or an intellectual disability.

CONCLUSIONS & IMPLICATIONS

This study has two key findings. First, autistic adults in the Netherlands experienced substantially higher loneliness and stress levels than non-autistic adults during lockdowns of the COVID-19 pandemic. Preventive and supportive measures to improve the wellbeing of autistic adults may focus on strengthening the social networks of autistic people, as our findings hint at perceived social support playing an important protective role. Second, it is unclear whether the pandemic-related restrictions exacerbated feelings of loneliness and stress in our autistic participants, because at a group level such feelings generally remained stable over an 8-months period. However, there were large individual differences in levels of and changes in loneliness and stress over time, indicating that the social restrictions may have been beneficial for some, but disadvantageous for others. Specifically, autistic adults with relatively many concerns about COVID-19 and who experienced insufficient social support were more likely to report higher levels of loneliness and stress during the first lockdown in the Netherlands. Also, adults with a prior mental health diagnosis were more likely to increase in their stress level over the course of the pandemic. The latter finding suggests that the COVID-19 pandemic and its associated restrictions have had a particularly negative effect on the mental health of people with a pre-pandemic vulnerability. Individual and environmental sources of variability in mental health outcomes of autistic adults require further study to inform who is most likely to need support during a nationwide or global crisis.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

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