

Mental health of autistic adults during the COVID-19 pandemic: The impact of perceived stress, intolerance of uncertainty, and coping style

Autism

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Abstract

Autistic individuals are at particular risk of experiencing mental health problems during the COVID-19 pandemic, yet little is known about personal characteristics that may underlie this vulnerability. This longitudinal questionnaire study with 149 autistic and 147 non-autistic adults investigated the association between perceived stress and anxiety and depressive symptoms, measured 4 months later. In addition, the moderating impact of intolerance of uncertainty and coping styles on this association was examined. Confirming previous studies, autistic adults reported poorer mental health than non-autistic individuals. Results demonstrated similar moderation models across individuals with versus without autism. Perceived stress at timepoint 1 was associated with anxiety and depression at timepoint 2. Across both participant groups, individuals with maladaptive coping strategies and higher levels of intolerance of uncertainty at timepoint 1 showed more internalizing symptoms at timepoint 2. The findings demonstrate the burden of the pandemic on the mental health of autistic adults, especially on those with high levels of perceived stress, maladaptive coping strategies, or intolerance of uncertainty. Interventions to support autistic adults during and after the pandemic might involve providing psychoeducation about the impact of stress, coping, and intolerance of uncertainty on internalizing symptoms, and teaching more adaptive ways to cope with difficult circumstances.

Lay abstract

More and more research shows us that autistic individuals are at risk of experiencing mental health problems in response to the COVID-19 pandemic. However, little is known about why this is the case. At two timepoints during the pandemic, we asked 149 autistic and 147 non-autistic adults about feelings of anxiety, depression, and stress, and about characteristics that may explain why some (autistic) people have a larger chance of developing anxiety and depression during this pandemic. In our study, autistic adults experienced more anxiety and depression than non-autistic adults. Across autistic and non-autistic individuals, the people who experienced more stress at timepoint 1 experienced more anxiety and depression 4 months later. This was especially the case for those individuals who use maladaptive coping styles, such as denial or venting, and for those who have difficulties dealing with uncertain situations. Our findings show the burden of the COVID-19 pandemic on the mental health of autistic adults. Interventions to support autistic adults during and after the pandemic are needed, and they may want to focus on the negative impact of stress and teach autistic (and non-autistic) adults more adaptive ways to cope with stressful circumstances.

Keywords

adults, anxiety, autism, coping, depression, intolerance of uncertainty COVID-19 pandemic, perceived stress, questionnaire

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From December 2019, the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) that causes coronavirus disease 2019 (COVID-19) started spreading worldwide. By April 2021, more than 111.4 million global cases were confirmed, resulting in 3.1 million deaths (World Health Organization, 2021). Elevated levels of stress, anxiety, and depression have been reported in the general population (Fancourt et al., 2021; Salari et al., 2020; Vindegaard & Benros, 2020; Xiong et al., 2020) and individuals with pre-pandemic mental health conditions have experienced an exacerbation of presenting difficulties during the COVID-19 pandemic (Vindegaard & Benros, 2020; Yao et al., 2020).

Given the high prevalence of co-occurring anxiety disorders and depression among autistic individuals¹ (Hollocks et al., 2019; Lai et al., 2019), this population may be considered particularly vulnerable to the negative effects of the COVID-19 pandemic on mental health (Ameis et al., 2020). Emerging empirical evidence suggests autistic people have experienced elevated mental health issues in response to the pandemic and the related restrictions (e.g. stay-at-home and social distancing mandates). A large-scale survey from the National Autistic Society in the United Kingdom, with 1810 autistic people and 2422 family members, revealed that 9 out of 10 individuals worried about their mental health (National Autistic Society, 2020). Individuals with autism report more emotional symptoms (Adams et al., 2021; Bal et al., 2021; Bundy et al., 2021; Cost et al., 2021; National Autistic Society, 2020; Oomen et al., 2021) and behavioral problems (Mutluer et al., 2020; Nonweiler et al., 2020) compared to before the pandemic. This increase in mental health problems seems to be larger in autistic adults compared to non-autistic individuals (Oomen et al., 2021) and compared to peers with other pre-pandemic mental health issues (Cost et al., 2021). In particular, adults with autism who were younger, female, had a prior mental health diagnosis, had a COVID-19 experience (that they defined as knowing someone who had COVID-19), or felt hopeless, showed the greatest negative impact of the pandemic on their daily life (Bal et al., 2021). Furthermore, surveys completed by 276 autistic adults before and 10 weeks after COVID-19 was declared a pandemic showed that pre-pandemic symptoms of anxiety and depression were significant predictors of anxiety and depression during the pandemic (Adams et al., 2021). However, further insight is needed into individual differences that may contribute to high levels of anxiety and depression in autistic people during the COVID-19 pandemic.

Abundant research in the general population demonstrates a strong association between stress and mental health problems (Lupien et al., 2009). However, anxiety and depression are not directly caused by stressful events; rather, they result from how individuals cope with these situations (Lazarus, 2006; Lazarus & Folkman, 1984).

Coping refers to the set of cognitive and behavioral strategies individuals apply to try to manage and regulate demands, pressures, and emotions in response to stress (Lazarus, 2006; Lazarus & Folkman, 1984). Several coping strategies can be differentiated, with some strategies resolving the stressful situation and resulting in positive effects on mental well-being. Such strategies are often referred to as adaptive coping strategies. Conversely, maladaptive coping strategies may not resolve stressful situations and can be associated with the development and maintenance of mental health problems (e.g. Kelly et al., 2008; Mahmoud et al., 2012; Wongtongkam, 2019). Large-scale studies suggest that such adaptive and maladaptive coping strategies have had a significant impact on symptoms of anxiety and depression in the general population during the COVID-19 pandemic (Dawson & Golijani-Moghaddam, 2020; Gurvich et al., 2020; Skapinakis et al., 2020).

Autistic adults identify a large number of stress-inducing situations in their everyday lives (Bishop-Fitzpatrick et al., 2017; Goodwin et al., 2007); data suggest stress-related problems may have increased during the COVID-19 pandemic. Bundy et al. (2021) found that more than half of the 133 adults with autism in their survey study said they experienced higher levels of stress due to the COVID-19 pandemic or related restrictions compared to before. In addition to high levels of perceived stress, autistic individuals generally experience more difficulties coping with stressful events (Hirvikoski & Blomqvist, 2015) and negative emotions (Cai et al., 2018) compared to non-autistic people. Emerging evidence confirms an association between maladaptive coping strategies (e.g. rumination, self-blame, or avoidance) and internalizing behaviors in adolescents and adults with autism (Abell & Hare, 2005; Gotham et al., 2014; Hare et al., 2016; Khanna et al., 2014; Khor et al., 2014). Furthermore, findings suggest that autistic people may use different or fewer adaptive strategies to deal with negative emotions (Bauminger, 2004; Cai et al., 2018; Samson et al., 2012). Specifically with regard to the COVID-19 pandemic, autistic adults have reported experiencing difficulties coping with the impact of the pandemic on several domains of life (such as employment, school, and social life), and this seemed to be especially the case for autistic women. These coping problems appeared to have increased during the time-course of the pandemic (Bal et al., 2021). Adams and colleagues (2021) showed that over half of the autistic adults in their study reported experiencing difficulties coping with the changes in their lives due to COVID-19. To the authors' knowledge, there are no studies about the nature of their coping strategies during the pandemic, measured with standardized questionnaires.

Intolerance of uncertainty has recently received attention in the autism literature as a characteristic that renders some individuals more vulnerable to anxiety and depression when faced with stressful situations. Intolerance of

uncertainty is generally considered to cover two aspects: “(i) the desire for predictability and actively seeking certainty, and (ii) paralysis of thought and action in face of uncertainty” (Birrell et al., 2011, p. 1198). It is associated with increased anxiety and depression in the general population and in diverse clinical populations (for meta-analyses, see Gentes & Ruscio, 2011; Hong & Cheung, 2015). Not only are high levels of intolerance of uncertainty more common among autistic individuals compared to their non-autistic peers, the robust association with anxiety has also been confirmed (for a meta-analysis, see Jenkinson et al., 2020). Intolerance of uncertainty has been found to mediate the association between autistic traits and anxiety (Hwang et al., 2020; Maisel et al., 2016), which suggests that intolerance of uncertainty is an important concept in the development of anxiety in autistic people (South & Rodgers, 2017). Intolerance of uncertainty may therefore be considered an individual characteristic that increases or decreases the negative impact of stress on mental health.

The goal of this study was to provide further insight into the mental health of autistic and non-autistic adults during the COVID-19 pandemic, with a focus on symptoms of anxiety and depression. Based on other studies conducted during the pandemic, we expected significantly more anxiety and depressive symptoms in autistic than in non-autistic adults (Bal et al., 2021; Oomen et al., 2021). Specifically, we wanted to study the association between perceived stress and later anxiety and depressive symptoms during the pandemic in individuals with and without autism, using standardized measures. Based on abundant evidence in the general population from before the COVID-19 pandemic (Lupien et al., 2009), we hypothesized that a positive longitudinal association between perceived stress and later anxiety and depression symptoms would also be present during the pandemic, and also in autistic individuals. Building on previous studies conducted during the pandemic, we aimed to investigate individual characteristics that may underlie the increased vulnerability of autistic individuals to develop symptoms of anxiety and depression, here focusing on the moderating impact of coping strategies and intolerance of uncertainty. We hypothesized that the negative impact of perceived stress on later mental health would be greater in individuals who report high levels of intolerance of uncertainty and in those who use more maladaptive coping strategies and fewer adaptive coping strategies. As there are no published findings to date, we could not formulate hypotheses regarding the autism specificity of those moderating effects.

Methods

This study is part of the DiCE study, which is a longitudinal online survey study on the impact of the COVID-19 pandemic on mental health of autistic and non-autistic adults. Participants were followed up after 4, 6, and

12 months. This report focuses on data collected at the first and second timepoints (T1 and T2).

Participants

Adults with and without autism participated in this study. Inclusion criteria were related to age (18 years and older) and country of residence (Belgium, the Netherlands, or the United Kingdom). Participants were recruited via social media channels, and stakeholder organizations were asked to distribute information about this study. Participants had to be fluent in written Dutch or English. Data from 265 individuals were excluded, as they did not meet inclusion criteria ($n=30$), only filled out the informed consent and a limited number of T1 questions ($n=130$), or dropped out after T1 and did not complete the T2 survey ($n=105$). The final sample comprised 240 Dutch-speaking adults (169 females, 71 males) aged 18–74 years, and 56 English-speaking adults (40 females, 11 males, 5 other gender) aged 19–71 years.

These 296 participants were divided into two different groups (see Table 1 for detailed characteristics of both groups). The group with autism ($n=149$) comprised individuals reported to have a formal diagnosis of autism spectrum disorder (ASD) according to *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; or previous versions of the DSM, $n=125$) and individuals self-identifying as having autism ($n=24$). Twenty percent (30 out of 149) of autistic participants scored below threshold on the AQ-10. Forty-two percent ($n=64$) of the autism group reported having an additional diagnosis of an anxiety and/or depressive disorder (including related disorders, i.e. obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), and bipolar disorder). The group without autism comprised 147 individuals without an autism diagnosis. Seven percent ($n=11$) of them reported currently having an anxiety and/or depressive disorder. Eighteen percent of both autistic and non-autistic participants reported having had COVID-19.

Procedure

An online Qualtrics survey was developed, consisting of self-report questionnaires. This report focuses on the first and second timepoint (T1 and T2) of a longitudinal study with four timepoints. The T1 questionnaire was available for completion between June and September 2020 (Med = 7 July 2020, range = (24 June 2020; 13 September 2020)) and the questionnaire at T2 was available between November 2020 and January 2021 (Med = 17 November 2020, range = (4 November 2020; 8 January 2021)). In all three countries, the T1 period included months of relaxations of special measures, except for some local lockdown implementations in the North West of England and Antwerp (Belgium). In July, wearing face masks became compulsory again in most indoor spaces and in busy

Table 1. Sample characteristics and group differences.

		Autism (n = 149)	Non-autism (n = 147)	Autism vs non-autism <i>t/χ</i> ²	
Gender	Male	24% (n = 36)	31% (n = 46)	6.44*	
	Female	73% (n = 108)	69% (n = 101)		
	Other	3% (n = 5)	0% (n = 0)		
Age (years)	Mean (SD)	41.67 (12.08)	42.05 (13.54)	0.25	
Country of residence	Belgium	59% (n = 88)	78% (n = 115)	13.55**	
	The Netherlands	15% (n = 22)	10% (n = 15)		
	United Kingdom	26% (n = 39)	12% (n = 17)		
Ethnicity	% White	97%	99%	1.28	
Living situation	Living alone vs together living with child(ren) vs without	43% vs 57%	11% vs 89%	37.66**	
		(n = 60 vs n = 80)	(n = 15 vs n = 127)		
		35% vs 65%	62% vs 38%		
Level of education		(n = 44 vs n = 82)	(n = 81 vs n = 50)	13.01**	
		Low	4% (n = 4)		0% (n = 0)
		Moderate	22% (n = 24)		9% (n = 12)
Occupational status		High	74% (n = 80)	91% (n = 116)	5.49
		Unemployed	28% (n = 41)	19% (n = 28)	
		Employed (part-time)	34% (n = 50)	31% (n = 46)	
		Employed (full-time)	33% (n = 49)	46% (n = 67)	
Other mental health diagnosis		Other	5% (n = 7)	4% (n = 6)	52.27**
		Anxiety disorder (no depressive disorder) ^a	11% (n = 17)	5% (n = 8)	
		Depressive disorder (no anxiety disorder) ^b	17% (n = 25)	1% (n = 2)	
		Anxiety ^a and depressive disorder ^b	14% (n = 21)	1% (n = 1)	
AQ-10	M (SD)	58% (n = 86)	93% (n = 136)	-20.69**	
		7.19 (2.12)	2.33 (1.92)		
Physical health		No anxiety or depressive disorder	56% (n = 83)	75% (n = 110)	11.93**
		44% (n = 66)	25% (n = 37)		
COVID-19 infection		No	82% (n = 122)	82% (n = 120)	0.01
		Yes ^c	18% (n = 27)	18% (n = 27)	

SD: standard deviation.

^aIncluding obsessive compulsive disorder (OCD) and post-traumatic stress disorder (PTSD). ^bIncluding bipolar disorder. ^cAs testing strategies showed strong regional differences, individuals with confirmed infections (based on COVID-19 or antivirus test) and individuals who suspected themselves to have (had) COVID-19 were merged into one category.

p* < 0.05; *p* < 0.01.

outdoor spaces in Belgium and in the United Kingdom, but not the Netherlands. From 18 August 2020 onward, the number of visitors was restricted per household in the Netherlands. During the T2 period, a strict set of regulations was re-introduced, including lockdowns, in all three countries with small local differences in the implementation. In the United Kingdom, a strict set of regulations were implemented from 5 November onward, and in Belgium, a national lockdown was introduced from 2 November 2020 onward. In the Netherlands, first, a partial lockdown was introduced (focusing on closing the eat-in options in bars and restaurants), and a strict lockdown was implemented 14 December 2020 onward.

On average, there were approximately 4 months between T1 and T2 responses, and this did not differ between individuals with versus without autism. At T1, perceived stress,

intolerance of uncertainty, coping strategies, and background variables were measured. From T2 data collection, we focus on anxiety and depression symptom self-report. This study was approved by the Social and Societal Ethics Committee (SMEC) of KU Leuven and the Research Ethics Committee of King's College London. All participants provided online informed consent and were invited to participate in a prize draw (five times €50 voucher in the Dutch-speaking sample and five times £50 voucher in the English-speaking sample).

Measures

The online questionnaire included a number of self-developed and standardized/normed questionnaires. In addition to the questionnaires mentioned below,

questions about the impact of the COVID-19 situation on different domains of life and questionnaires about traumatic experiences were included, but they are not the focus of this study.

Background information.² Participants were asked to provide information about their country of residence, gender, age, ethnicity, living situation, level of education, employment status, current physical health, perceived risk of contracting COVID-19, experience of contracting COVID-19, autism diagnosis, and current mental health diagnoses (this was an open question). Participants were also asked to complete the short version of the Autism Spectrum Quotient (AQ-10), as a measure of autistic traits (Allison et al., 2012). In the sections below, we focus on the questionnaires that were further analyzed in this article. Internal consistency of each questionnaire, as measured by Cronbach's α , was calculated based on the responses of the autism and non-autism groups separately.

Perceived stress. The Perceived Stress Scale (PSS-10) measured perceptions of stress using 10 items on a 5-point scale (S. Cohen et al., 1983). Individuals with total scores below 14 are considered to have low levels of perceived stress, scores between 14 and 26 suggest moderate levels of stress, and scores of 27 and higher suggest high levels of stress. In the general population, the PSS-10 has demonstrated an adequate construct validity and good reliability (Cronbach's α between 0.78 and 0.91; S. Cohen & Janicki-Deverts, 2012; S. Cohen & Williamson, 1988). For autistic adults specifically, the instrument has shown good internal consistency, with Cronbach's α of 0.87 (Bishop-Fitzpatrick et al., 2017, 2018). In our data, Cronbach's $\alpha=0.82$ for autistic adults, and $\alpha=0.80$ in the non-autistic group.

Anxiety symptoms. The Generalized Anxiety Disorder (GAD-7) is a seven-item screening questionnaire for general anxiety on a 4-point scale, with the following reference scores: 0–4 representing minimal anxiety, 5–9 mild anxiety, 10–14 moderate anxiety, and scores between 15 and 21 suggesting severe anxiety (Spitzer et al., 2006). In the general population, the GAD-7 has an excellent internal consistency (Cronbach's $\alpha=0.92$), and good test–retest reliability (intra-class correlation=0.83; Spitzer et al., 2006). To the authors' knowledge, psychometric properties have not been evaluated specifically for autistic individuals. Our data confirmed the excellent internal consistency of the GAD-7 in individuals with and without autism separately (Cronbach's $\alpha=0.93$ and 0.91, respectively).

Depression symptoms. The Patient Health Questionnaire (PHQ-9) was used to assess the severity of depressive symptoms in nine items on a 4-point scale (Kroenke et al., 2001). The authors suggested the following reference points: scores between 0 and 4 indicate minimal

depression, between 5 and 9 mild depression, between 10 and 14 moderate depression, between 15 and 19 moderately severe depression, and between 20 and 27 severe depression (Kroenke et al., 2001). The PHQ-9 has demonstrated excellent internal consistency in autistic and non-autistic adults (for both groups: Cronbach's $\alpha=0.91$), and good convergent validity (as demonstrated by strong correlations with measures of well-being; Arnold et al., 2020). The excellent internal consistency was confirmed in our sample: Cronbach's α (autism group)=0.91, Cronbach's α (non-autism group)=0.86.

Coping. The Brief COPE is a 28-item instrument that explores a set of 14 different coping strategies people can use across settings, with two items on a 4-point scale for each coping strategy (Carver, 1997). The 14 coping strategies can be combined into maladaptive strategies (including denial, self-blame, substance use, venting, behavioral disengagement, and self-distraction) and adaptive coping strategies (including planning, seeking emotional support, positive reframing, active coping, acceptance, seeking informational support, humor, and religion; Mahmoud et al., 2012; Rettie & Daniels, 2020). Scores for the six maladaptive and eight adaptive strategies are summed to give maladaptive and adaptive coping scores, with higher scores representing more frequent use of the strategies. In the general population, the adaptive and maladaptive scales have shown good internal consistency (Cronbach's $\alpha=0.88$ and 0.81; Mahmoud et al., 2012). To the authors' knowledge, psychometric properties have not been evaluated specifically for autistic individuals. Our data showed Cronbach's α of 0.69 for autistic and non-autistic individuals for the adaptive strategies, and of 0.81 for autistic and of 0.87 for non-autistic adults for the maladaptive strategies.

Intolerance of uncertainty. The Intolerance of Uncertainty Scale (IUS-12) is a 12-item instrument assessing the reactions of participants to uncertainty, ambiguous situations, and the future, on a 5-point scale, with higher scores indicating higher levels of intolerance to uncertainty (Carleton et al., 2007). In the general population, the instrument has demonstrated a good convergent and discriminant validity, and a good internal consistency with Cronbach's α of 0.96 (Carleton et al., 2007). Recently, the IUS-12 has been reported to show excellent internal consistency in autistic adults, with Cronbach's α of 0.91 (Moore et al., 2022). Our data confirmed this, with Cronbach's α of 0.91 for autistic and for non-autistic participants.

Data analysis

All analyses were conducted using SPSS. Assumptions were checked, and an α level of 0.05 was adopted. Descriptive statistics, independent samples t tests, and χ^2

were calculated to examine group differences on the variables of interest. Correlational analyses were conducted to examine the association between the variables of interest, and also to check for collinearity between independent variables that are included in one moderation model. Moderation models were then tested in the autistic and non-autistic participant groups separately using the PROCESS tool with 5000 resamples (Hayes, 2017), including age, having (had) a COVID-19 infection, gender, and baseline mental health disorders (anxiety disorder, including OCD and PTSD, and/or depressive disorder, including bipolar disorder) as covariates. COVID-19 infections were included as dummy variable (0=not had COVID-19 infection and 1=had COVID-19 infection). Gender was also included as dummy variable (in the non-autistic adults: gender: 0=female, 1=male; in the autistic adults: gender male: 0=female or other, 1=male; gender other: 0=female or male, 1=other). We controlled for baseline mental health by including the self-reported current diagnoses in the model. For this reason, having at least one co-occurring self-reported anxiety, depressive, or related disorder was also included as dummy variable (0=no co-occurring mental health disorder and 1=at least one co-occurring mental health disorder). Post hoc exploratory partial correlations were conducted to better understand discrepancies between results from the correlational analyses and the moderation models. J. Cohen's (1988) guidelines were used to interpret correlations as small ($r > 0.10$), moderate ($r > 0.30$), or large ($r > 0.50$) and to interpret Hedges' g values as small ($g > 0.20$), medium ($g > 0.50$), or large ($g > 0.80$).

Community involvement

This online questionnaire was developed in collaboration with a group of autistic adults to ensure the clarity of the questions.

Results

Differences in anxiety, depression, perceived stress, coping, and intolerance of uncertainty between autistic and non-autistic adults

Autistic adults reported significantly higher symptoms of anxiety and depression (measured at T2), and more perceived stress (measured at T1), compared to non-autistic adults. In addition, autistic individuals scored significantly higher on intolerance of uncertainty, maladaptive coping, and lower on adaptive coping during T1. Autistic adults demonstrated much higher rates of perceived stress (34% of the autistic adults reported high levels of stress at T1 vs 8% of the non-autistic adults), higher rates of anxiety symptoms (23% of the autistic adults reported severe levels of anxiety on the GAD-7 at T2 vs 3% of the non-autistic adults), and higher rates of depressive symptoms (17% of the autistic adults reported severe depression on

the PHQ-9 at T2 vs 2% of the non-autistic adults) than the non-autistic individuals. Effect sizes were small to medium for coping styles, and large for the other variables (see Table 2).

Correlational analyses

In autistic participants (see Table 3 above the diagonal), the correlation between anxiety and depression at T2 was large. Perceived stress, measured at T1, was also significantly correlated with T2 anxiety and depression, both with large effect sizes. Intolerance of uncertainty at T1 was moderately associated with later anxiety and depression. Neither the association between adaptive coping and anxiety nor between adaptive coping and depression was significant. Maladaptive coping, on the other hand, was significantly correlated with later anxiety and depression. Correlations between variables of interest that will be included in the same moderation model (i.e. adaptive coping, maladaptive coping, and perceived stress on the one hand, and intolerance of uncertainty and perceived stress on the other hand) were smaller than $|0.50|$, which does not suggest collinearity between independent variables.

In non-autistic adults (see Table 3 below the diagonal), there was a large correlation between anxiety and depression at T2. Perceived stress at T1 was also significantly associated with later anxiety and depression. The correlation between intolerance of uncertainty and later anxiety symptoms was large, while intolerance of uncertainty and T2 depression symptoms were moderately associated.

Variables of interest that will be included in the same moderation model (i.e. adaptive coping, maladaptive coping, and perceived stress, on the one hand, and intolerance of uncertainty and perceived stress, on the other hand) correlated no more than 0.57, which does not suggest collinearity between independent variables.

Moderating effect of maladaptive and adaptive coping on the association between timepoint 1 (T1) perceived stress and timepoint 2 (T2) anxiety

In autistic adults, the overall model including T1 perceived stress as a predictor, moderated by adaptive and maladaptive coping strategies, and with age, gender, COVID-19 infection, and self-reported mental health diagnosis as covariates, significantly predicted anxiety symptoms at T2 ($R^2 = 0.37$, $F(10, 138) = 8.10$, $p < 0.001$; see Figure 1 and for more details, see Supplementary Material Table S1). Perceived stress at T1 significantly predicted T2 anxiety. The included covariates did not significantly predict later-on anxiety. Adaptive coping did not have a significant main or moderating ($\Delta R^2 = 0.001$, $F(1, 138) = 0.21$, $p = 0.651$) effect on T2 anxiety. Maladaptive coping significantly predicted more anxiety symptoms at T2 in autistic adults, but maladaptive

Table 2. Mental health, intolerance of uncertainty and coping strategies in adults with versus without autism.

	Autism (<i>n</i> = 149)		Non-autism (<i>n</i> = 147)		Autism vs non-autism	
	M (SD)	Min–max	M (SD)	Min–max	<i>t</i> test	Hedges' <i>g</i>
Anxiety _(T2) (max = 21)	8.79 (6.12)	0–21	4.84 (4.25)	0–21	−6.47**	0.75
Depression _(T2) (max = 27)	10.57 (7.00)	0–27	5.30 (4.64)	0–23	−7.65**	0.89
Perceived stress _(T1) (max = 40)	23.49 (7.03)	4–36	16.95 (5.85)	5–35	−8.71**	1.01
Adaptive coping _(T1) (max = 64)	34.44 (6.88)	17–58	37.12 (7.53)	22–60	3.20**	−0.37
Maladaptive coping _(T1) (max = 48)	22.54 (4.92)	12–35	20.10 (3.91)	12–33	−4.74**	0.55
Intolerance of uncertainty _(T1) (max = 60)	44.59 (9.00)	17–60	30.02 (9.30)	13–59	−13.70**	1.59

SD: standard deviation.

^aAt timepoint 2, two non-autistic participants did not complete the PSS.

***p* < 0.01.

Table 3. Correlations for the autistic adults (above the diagonal) and the non-autistic adults (below the diagonal): Pearson *r* (*p* value between brackets).

	Perceived stress _{T1}	Intolerance of Uncertainty _{T1}	Maladaptive coping _{T1}	Adaptive coping _{T1}	Anxiety _{T2}	Depression _{T2}
Perceived stress _{T1}		0.36 (<0.001)**	−0.49 (<0.001)**	−0.06 (0.45)	0.56 (<0.001)**	0.53 (<0.001)**
Intolerance of Uncertainty _{T1}	0.52 (<0.001)**		0.44 (<0.001)**	−0.10 (0.23)	0.40 (<0.001)**	0.36 (<0.001)**
Maladaptive coping _{T1}	0.56 (<0.001)**	0.32 (<0.001)**		0.25 (0.002)**	0.40 (<0.001)**	0.40 (<0.001)**
Adaptive coping _{T1}	0.11 (0.18)	−0.14 (0.09)	0.48 (<0.001)**		−0.05 (0.51)	−0.06 (0.48)
Anxiety _{T2}	0.65 (<0.001)**	0.53 (<0.001)**	0.50 (<0.001)**	0.14 (0.09)		0.78 (<0.001)**
Depression _{T2}	0.60 (<0.001)**	0.39 (<0.001)**	0.47 (<0.001)**	0.07 (0.37)	0.73 (<0.001)**	

***p* < 0.01.

coping did not significantly moderate the association between T1 perceived stress and T2 anxiety ($\Delta R^2=0.01$, $F(1, 138)=1.74$, $p=0.189$).

In non-autistic adults, the overall model including perceived stress as a predictor, moderated by adaptive and maladaptive coping strategies, and with age, gender, COVID-19 infection, and self-reported mental health diagnoses as covariates, significantly predicted anxiety symptoms at T2 ($R^2=0.49$, $F(9, 137)=14.39$, $p<0.001$; see Figure 1 and for more details, see Supplementary Material Table S1). Perceived stress significantly predicted later anxiety. The included covariates did not significantly predict anxiety. Adaptive coping did not have a significant effect on T2 anxiety, and it also did not moderate the association between perceived stress and anxiety ($\Delta R^2=0.001$, $F(1, 137)=0.35$, $p=0.553$). Maladaptive coping significantly predicted more anxiety in individuals without autism, but it did not significantly moderate the association between perceived stress and T2 anxiety ($\Delta R^2=0.01$, $F(1, 137)=1.68$, $p=0.197$).

Moderating effect of maladaptive and adaptive coping on the association between timepoint 1 (T1) perceived stress and timepoint 2 (T2) depression

The overall model including T1 perceived stress as a predictor, moderated by adaptive and maladaptive coping

strategies, and age, gender, COVID-19 infection, and self-reported mental health diagnosis as covariates significantly predicted depressive symptoms at T2 in the autistic adults ($R^2=0.39$, $F(10, 138)=8.81$, $p<0.001$; see Figure 1, and for more details, see Supplementary Material Table S2). Perceived stress significantly predicted later depression symptoms and having at least one co-occurring mental health diagnosis was a significant covariate. Age, gender, and having experienced a COVID-infection were not significant covariates in the model. In the autism group, there was no main or moderation effect ($\Delta R^2=0.001$, $F(1, 138)=0.17$, $p=0.683$) of adaptive coping on T2 depression. Using maladaptive coping strategies significantly predicted T2 depressive symptoms, but did not significantly moderate the association between perceived stress and T2 depression ($\Delta R^2=0.01$, $F(1, 138)=1.53$, $p=0.219$).

In non-autistic adults, the overall model including perceived stress as a predictor, moderated by adaptive and maladaptive coping strategies, and age, gender, COVID-19 infection, and self-reported mental health diagnosis as covariates significantly predicted depressive symptoms at T2 ($R^2=0.46$, $F(9, 137)=12.89$, $p<0.001$; see Figure 1, and for more details, see Supplementary Material Table S2). Perceived stress significantly predicted later depressive symptoms for non-autistic individuals, and the included covariates did not

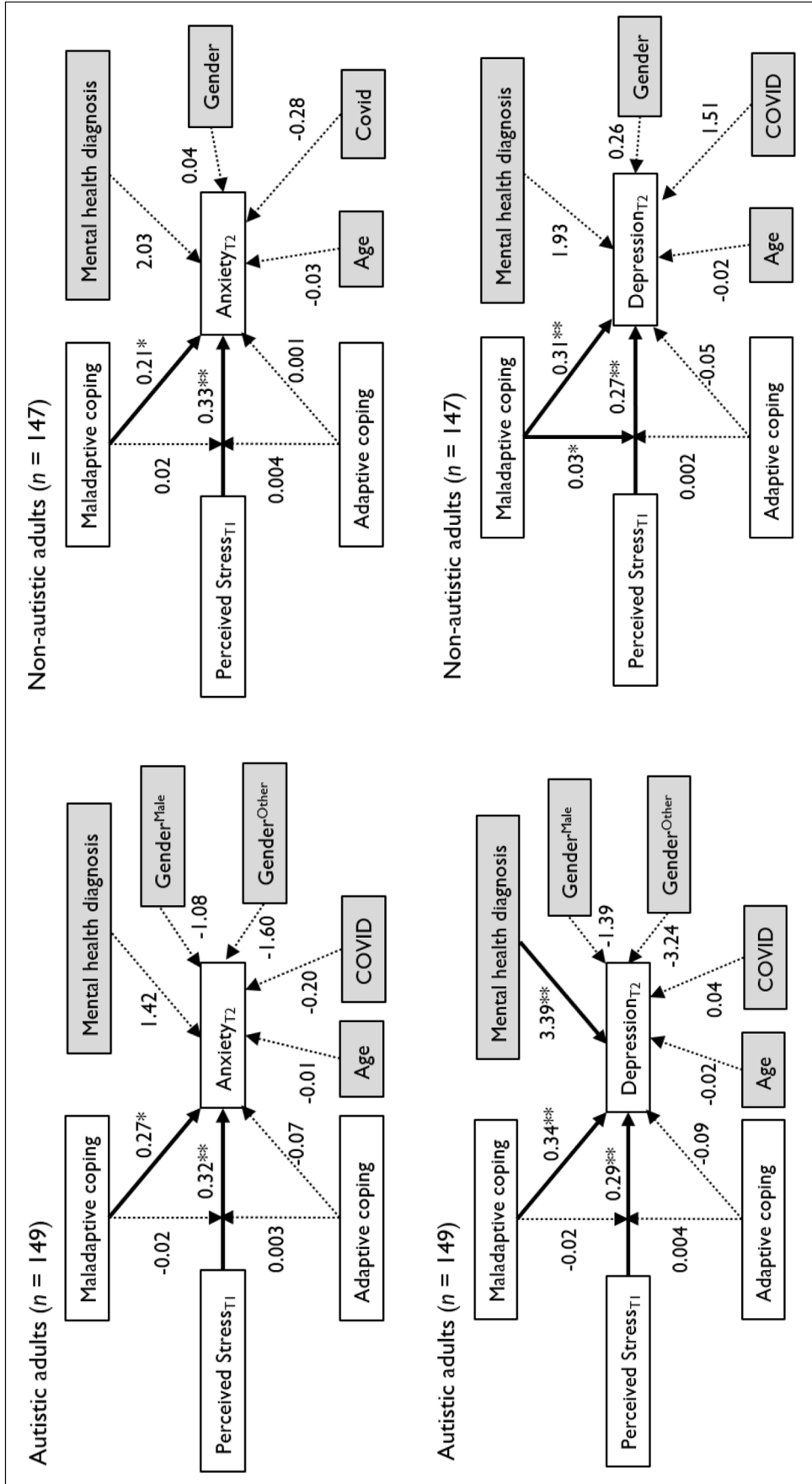


Figure 1. Unstandardized regression coefficients for autistic and non-autistic adults for the association between perceived stress and anxiety symptoms (top row) and depressive symptoms (bottom row), moderated by adaptive and maladaptive coping strategies, including age, COVID-19 infection, gender, and mental health diagnosis as covariates. Full arrows indicate significant associations, and dotted arrows indicate associations with *p* value above 0.05. **p* < 0.05; ***p* < 0.01. Covariates are in light-gray boxes.

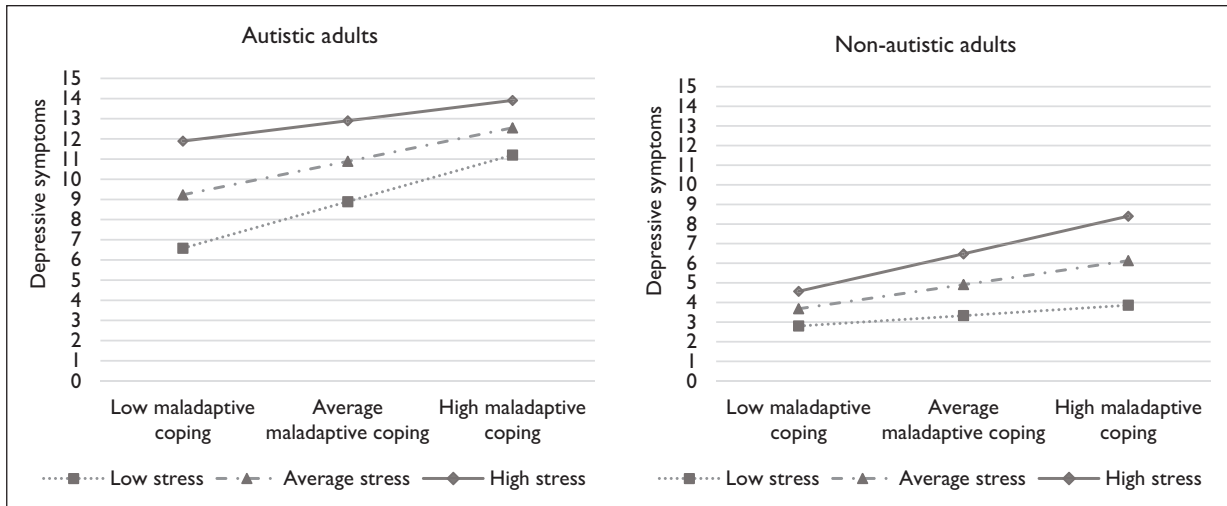


Figure 2. The association between perceived stress and depressive symptoms was not significantly moderated by maladaptive coping strategies in the autistic adults (on the left), but the moderation effect was significant in the non-autistic adults (on the right). The categories “low,” “average,” and “high” represent values 1 SD below the mean, the mean, and 1 SD above the mean, resp.

significantly predict depression. There was no (moderating) effect of adaptive coping on T2 depression (for the moderation effect: $\Delta R^2=0.001$, $F(1, 137)=0.04$, $p=0.834$). Using maladaptive coping strategies significantly predicted depressive symptoms at T2, and it also significantly moderated the association between perceived stress and T2 depression ($\Delta R^2=0.02$, $F(1, 137)=5.42$, $p=0.021$, see Figure 2); the effect of perceived stress on later depressive symptomatology was stronger for those using more maladaptive coping strategies.

Moderating effect of intolerance of uncertainty on the association between timepoint 1 (T1) perceived stress and timepoint 2 (T2) anxiety

In autistic adults, the overall model including perceived stress as a predictor, moderated by intolerance of uncertainty, and age, gender, COVID-19 infection, and self-reported mental health diagnosis as covariates significantly predicted anxiety severity at T2 ($R^2=0.35$, $F(8, 140)=9.42$, $p<0.001$). Perceived stress was a significant predictor of later anxiety symptoms, and none of the covariates significantly predicted anxiety at T2. Intolerance of uncertainty did not significantly predict T2 anxiety (see Figure 3, and for more detailed information, see Supplementary Material Table S3). Furthermore, intolerance of uncertainty did not significantly moderate the association between perceived stress and later anxiety in adults with autism ($\Delta R^2=0.001$, $F(1, 140)=0.24$, $p=0.622$). To better understand the discrepancy between the results of the correlational analyses, which showed a moderate association between intolerance of uncertainty and T2 anxiety, and the lack of significant main or moderation effect of intolerance of uncertainty in the moderation analyses, exploratory post hoc analyses

were conducted, consisting of partial correlations. These partial correlations demonstrated that the moderate correlation between intolerance of uncertainty and T2 anxiety falls below significance when controlling for T1 perceived stress in the autism group (see Supplementary Table S5).

In non-autistic adults, the overall model including perceived stress as a predictor, moderated by intolerance of uncertainty, and age, gender, COVID-19 infection, and self-reported mental health diagnosis as covariates significantly predicted anxiety at T2 ($R^2=0.50$, $F(7, 139)=19.47$, $p<0.001$). Perceived stress significantly predicted later anxiety symptoms, and the effects of the covariates were not significant. In non-autistic individuals, intolerance of uncertainty significantly predicted T2 anxiety (see Figure 3, and for more detailed information, see Supplementary Material Table S3). However, intolerance of uncertainty did not significantly moderate the association between perceived stress and anxiety ($\Delta R^2=0.004$, $F(1, 139)=1.11$, $p=0.294$).

Moderating effect of intolerance of uncertainty on the association between perceived stress at timepoint 1 (T1) and timepoint 2 (T2) depression

In autistic individuals, the overall model including perceived stress as a predictor, moderated by intolerance of uncertainty, and age, gender, COVID-19 infection, and self-reported mental health diagnosis as covariates significantly predicted depressive symptoms at T2 ($R^2=0.36$, $F(8, 140)=9.76$, $p<0.001$; see Figure 3, and for more details, see Supplementary Material Table S4). Age, gender, and having had a COVID-19 infection did not predict later depression. Autistic individuals who self-reported at

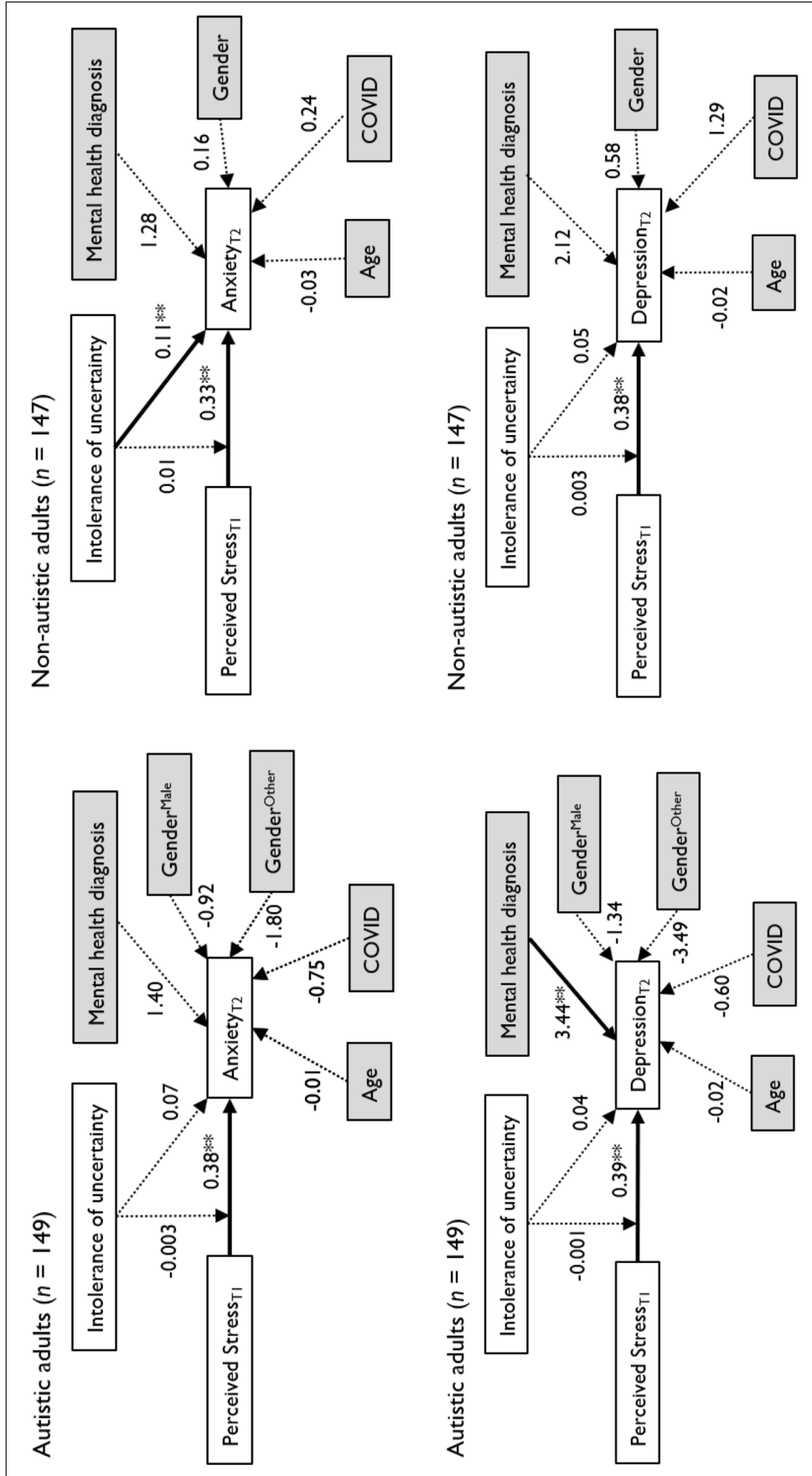


Figure 3. Unstandardized regression coefficients for autistic and non-autistic adults for the association between perceived stress and anxiety symptoms (top row) and depressive symptoms (bottom row), moderated by intolerance of uncertainty, including age, COVID-19 infection, gender, and mental health diagnosis as covariates. Full arrows indicate significant associations, and dotted arrows indicate associations with p value above 0.05. * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. Covariates are in light-gray boxes.

least one mental health diagnosis showed significantly more depressive symptoms at T2. Perceived stress significantly predicted later depressive symptoms. There was no (moderating) effect of intolerance of uncertainty on T2 depression (for the moderation effect: $\Delta R^2=0.001$, $F(1, 140)=0.04$, $p=0.836$).

In non-autistic adults, the overall model including T1 perceived stress as a predictor, moderated by intolerance of uncertainty, and age, gender, COVID-19 infection, and self-reported mental health diagnosis as covariates significantly predicted depression at T2 ($R^2=0.41$, $F(7, 139)=13.55$, $p<0.001$; see Figure 3, and for more details, see Supplementary Material Table S4). Age, gender, having had a COVID-19 infection, and self-reported mental health diagnosis did not predict later depressive symptoms. Perceived stress at T1 was significantly associated with later depression. Intolerance of uncertainty, however, did not have a significant effect on T2 depression, and the intolerance of uncertainty did not significantly moderate the association between T1 perceived stress and later depression ($\Delta R^2=0.001$, $F(1, 139)=0.23$, $p=0.635$). To better understand the discrepancy between these results and the moderate correlation between intolerance of uncertainty and T2 depression reported above, exploratory post hoc analyses were conducted, consisting of partial correlations. These partial correlations demonstrated that the moderate correlation between intolerance of uncertainty and T2 depression fell below significance after controlling for T1 perceived stress (see Supplementary Materials Table S5).

Discussion

Using standardized self-report measures of facets of mental health, this study showed that autistic adults experienced significantly more perceived stress, anxiety, and depressive symptoms compared to non-autistic adults during early stages of the COVID-19 pandemic. Perceived stress at T1 was significantly associated with later anxiety and depression in individuals with and without autism. Individual characteristics such as maladaptive coping styles and intolerance of uncertainty played an important role in the association between stress and mental health, albeit the exact nature of their role differed between participant groups (autistic vs non-autistic adults) and symptomatology (anxiety vs depressive symptoms).

More mental health problems among autistic than non-autistic adults during the pandemic

Recent reviews have demonstrated elevated mental health problems in the general population during the COVID-19 pandemic (Vindegaard & Benros, 2020; Xiong et al., 2020). The average scores of the non-autistic participants in our study represented minimal anxiety, but showed mild

depressive symptoms and moderate levels of perceived stress during this phase of the pandemic. Unfortunately, the autistic adults in our study demonstrated much higher rates of perceived stress, higher rates of anxiety symptoms, and higher rates of depressive symptoms than the non-autistic individuals. Such a clear vulnerability of autistic people in experiencing internalizing problems during the pandemic was also demonstrated in other studies (Bal et al., 2021; Bundy et al., 2021; National Autistic Society, 2020; Oomen et al., 2021), and might partially reflect the presence of pre-pandemic mental health issues among individuals with autism (Hollocks et al., 2019), with the COVID-19 pandemic increasing these existing problems (Adams et al., 2021).

Strong association between perceived stress and mental health

This study provided clear evidence for an association between T1 perceived stress and later-on anxiety and depressive symptoms in autistic and non-autistic individuals. A recent literature review (Thoen et al., 2021) reported only three studies (two of them using the same group of participants) that examined perceived stress of autistic adults using the PSS-10, and no research on the association between perceived stress (measured with the PSS) and mental health problems in autistic individuals. The size of the association between perceived stress and later anxiety and depressive symptoms, in this study, was similar across autistic and non-autistic adults, as demonstrated by large correlations in both groups.

Based on the reported data, we cannot say if stress levels in our autistic participants are heightened during this pandemic or reflect higher levels of pre-pandemic stress, yet other studies have demonstrated increased levels of stress in the majority of autistic (Bundy et al., 2021) and non-autistic adults (Vindegaard & Benros, 2020; Xiong et al., 2020) in response to the COVID-19 pandemic. These findings underline the importance of stress in the development and maintenance of anxiety and depression, which may be particularly relevant during times of persistent, elevated stress such as the current pandemic.

The impact of (maladaptive) coping strategies

Findings by Bal and colleagues (2021) have shown that adults with autism experience problems with dealing with the impact of the COVID-19 pandemic on different domains of life, which is in line with known coping and emotion regulation difficulties (Cai et al., 2018; Hirvikoski & Blomqvist, 2015). This study is the first, to our knowledge, to use standardized questionnaires to demonstrate that autistic adults reported using more maladaptive coping strategies and fewer adaptive coping strategies during this pandemic, compared to non-autistic adults. Such a difference in coping

style may partially explain the elevated mental health problems found here, and reported elsewhere among autistic people in response to the COVID-19 pandemic (Bal et al., 2021; Bundy et al., 2021; National Autistic Society, 2020; Oomen et al., 2021).

Among autistic and non-autistic participants, self-reported use of maladaptive coping strategies (including denial, self-blame, substance use, venting, behavioral disengagement, and self-distraction) was moderately associated with later anxiety and depression. For non-autistic (but not autistic) participants, the effect of perceived stress on depressive symptoms was also stronger for those using more maladaptive coping strategies, as demonstrated by the moderation effect. Adaptive coping strategies (specifically planning, seeking emotional support, positive reframing, active coping, acceptance, seeking informational support, humor, and religion) were not associated with later depression or anxiety, in neither of both groups. The results of this study confirmed and expanded the findings of pre-pandemic studies that have shown a relationship between maladaptive coping and poor mental health in autistic individuals (Abell & Hare, 2005; Gotham et al., 2014; Hare et al., 2016; Khanna et al., 2014; Khor et al., 2014). Our findings demonstrated that maladaptive coping strategies also play an important role in the development and maintenance of later internalizing symptoms in individuals with and without autism during this pandemic. Furthermore, only for non-autistic participants, maladaptive coping strategies have an even stronger impact when individuals perceive more stress. This moderation effect was absent among autistic participants, which may suggest that using maladaptive coping strategies has a negative impact on mental health for autistic adults, irrespective of the amount of stress someone is experiencing. Alternatively, very high perceived stress in autism may swamp any moderating effect of maladaptive coping. Intervention designs could be informative for establishing causal links and directions.

The impact of intolerance of uncertainty

In line with prior work, we found higher levels of intolerance of uncertainty in autistic than non-autistic individuals (Jenkinson et al., 2020). Furthermore, intolerance of uncertainty was also moderately associated with later anxiety. A recent meta-analysis reported a large correlation between intolerance of uncertainty and anxiety in individuals with autism ($r=0.62$, 95% confidence interval (CI): 0.52, 0.71), based on cross-sectional data from 10 studies (Jenkinson et al., 2020). The size of the association we found was slightly lower ($r=0.40$). This could be due to several reasons: differences in age (our study only included adults, and the meta-analysis was based on autistic individuals across different ages) or respondents (we used self-reports, while in the meta-analysis proxy-reports were

also included), although age or type of respondent did not have an impact on the association between intolerance of uncertainty and anxiety in the meta-analysis (Jenkinson et al., 2020). The slightly smaller, yet still moderate, correlation between intolerance of uncertainty and anxiety in this study may reflect our use of longitudinal data, instead of cross-sectional data, as in the studies in the meta-analysis. Similar results were found for our non-autistic participants: intolerance of uncertainty was associated with symptoms of depression and anxiety 4 months later. The association with later anxiety seemed larger than with depression in non-autistic individuals, but CIs based on Fisher's r -to- z transformation overlapped ($r_{\text{intolerance of uncertainty} - \text{later depression}}$: 95% CI: 0.24, 0.52; $r_{\text{intolerance of uncertainty} - \text{later anxiety}}$: 95% CI: 0.40, 0.64), suggesting that the sizes of both correlations were not statistically different.

The findings of this study therefore suggest that intolerance of uncertainty may predict later mental health problems (South & Rodgers, 2017); greater intolerance of uncertainty was associated with increased levels of anxiety and depression 4 months later in autistic and non-autistic adults. However, after controlling for perceived stress, intolerance of uncertainty did not have a significant impact on later anxiety or depression in autistic adults. This may suggest that the association between intolerance of uncertainty and mental health in autistic individuals is influenced by or can be attributed to perceived stress. These findings may also partially reflect the larger effect size of the association between perceived stress and later internalizing problems compared to the effect size of the association between intolerance of uncertainty and mental health, which might swamp the effect of the latter. As this study was the first to examine the combined role of perceived stress and intolerance of uncertainty on later internalizing problems, future work is needed to provide more insight in their association. In non-autistic participants, the association between intolerance of uncertainty and later anxiety—but not depression—remained significant after controlling for perceived stress, which might reflect the stronger relationship between intolerance of uncertainty and anxiety compared to depression in the general population and in other clinical populations (Gentes & Ruscio, 2011; Hong & Cheung, 2015).

Limitations of this study

This study examined longitudinal data from two timepoints, approximately 4 months apart. A baseline (pre-pandemic) measure of anxiety and depression symptoms and perceived stress with the same instruments was not available in this study. We, therefore, included self-reported mental health diagnoses to control for mental health problems participants already experienced before the pandemic. Despite the limitations of this variable (e.g. higher threshold to attain an additional diagnosis in autistic

people and the self-reported and open text box nature of this question), it is the best estimate of baseline mental health available in this study. Even though our longitudinal data seem to suggest that maladaptive coping styles, high levels of perceived stress and high levels of intolerance of uncertainty result in more internalizing symptoms, we cannot exclude the reverse also being the case: individuals with poor mental health may experience more stress, therefore use more (maladaptive) coping strategies and become more intolerant of uncertainty. However, other studies have suggested a significant increase in internalizing problems in autistic individuals in response to the pandemic (Bal et al., 2021; Bundy et al., 2021; National Autistic Society, 2020; Oomen et al., 2021). Furthermore, intolerance of uncertainty is considered a (relatively) stable trait, but it is not known if highly volatile and uncertain situations, such as the COVID-19 pandemic, might trigger or exacerbate intolerance of uncertainty.

The internal consistency of the scale adaptive coping strategies fell below that of the maladaptive coping strategies scale and was also below that previously reported. Authors can hence not exclude that associations with adaptive coping were not observed because of limitations of the scale. Future work may wish to further evaluate the psychometric properties in autistic adults. The majority of autistic adults included in this study were female (71%), which is inconsistent with diagnostic rates (Loomes et al., 2017), but this sex ratio is similar to comparable online questionnaire studies (Oomen et al., 2021), and volunteer rates more generally. Moreover, a significant proportion (20%) of our autistic participants scored below cutoff on the AQ-10, which suggests a lower rate of autistic symptoms in current functioning in this sub-group, maybe even including individuals who would currently not meet clinical criteria for ASD. Furthermore, a significant proportion of the non-autistic group had experienced a (suspected) COVID-19 infection, which potentially suggests a selection bias; the advertisement for this study was also distributed on social media groups for people with long COVID-19. One may question the generalizability of our findings due to the over-representation of females, of autistic individuals scoring below cutoff on the AQ-10, and of people who experienced COVID-19. Although this should be explored in future studies, we note that our results showed a very limited influence of gender and/or COVID-19 experience on mental health problems in the models we ran.

The autism group was living apart more frequently than the non-autism group, and they also were less likely to have children. These differences in living situation might cause loneliness or parental stress/caregiver strain, which, in turn, could have an impact on mental health (e.g. Schiltz et al., 2021). However, an in-depth analysis of qualitative data reported by our participants revealed very diverse experiences of autistic individuals during the pandemic,

with some participants reporting a positive impact on their family life because of the increased amount of time spent together, while others mentioned an increased caregiver strain (Maljaars et al., 2022). The autism group also reported a poorer physical health compared to the non-autism group (a high level of physical comorbidity was also reported by e.g. Cashin et al., 2018), which might have caused higher levels of perceived stress. Future studies may seek to examine the impact of physical health on mental health in this group.

Data collection in this study took place between June and September 2020 (T1), a timespan comprising periods with a relaxation of containment measures (in June and July) and periods with locally implemented stricter regulations (in August and September), and between November 2020 and January 2021 (T2), a period with stricter regulations, but we did not assess mental health during specific lockdown restrictions. Data from a large-scale study in the general population in the United Kingdom showed that psychological problems were greatest right after the implementation of lockdown, and already started to decrease in weeks 2 to 5 after the instigation of lockdown (Fancourt et al., 2021). This could suggest that this study may present a relatively optimistic picture of the mental health of the participating adults, which may have been worse at earlier time points.

Conclusions and implications

Using standardized online questionnaires to collect longitudinal data from 296 adults in three countries, this study demonstrated more symptoms of anxiety and depression in autistic than non-autistic individuals during the COVID-19 pandemic. However, the factors underlying an increased vulnerability to experience mental health problems were in general rather similar across both participant groups. Individuals who experienced elevated levels of perceived stress at T1 showed more anxiety and depression symptoms 4 months later. The reported levels of probable mental health problems among autistic adults during the COVID-19 pandemic are worrisome and require further attention and additional mental health support for this population.

Our data suggest that interventions targeting potential underlying issues, such as perceived stress, maladaptive coping strategies, and intolerance of uncertainty, are worth exploring. Offering psychoeducation about the importance of perceived stress and maladaptive coping strategies in the development and maintenance of internalizing problems may be helpful. Autistic individuals could be taught to recognize signals of increased levels of stress and gain more insight into the potentially maladaptive strategies they use to cope with heightened stress levels. Interventions could then focus on supporting autistic individuals to develop additional reactive and

proactive adaptive ways for dealing with stress and negative feelings and reducing tendencies to engage in maladaptive coping styles. The pandemic has unfortunately been characterized by a significant degree of uncertainty, but policymakers should try to communicate transparently and create as much predictability as possible (e.g. by communicating clear targets for changes in COVID-19 regulations). Autistic individuals themselves may wish to increase predictability during these highly uncertain times, by, for example, following existing routines as much as possible, creating new routines for situations that have changed, or re-formulating uncertainties into certainties (Rodgers et al., 2020). Furthermore, those with high levels of intolerance of uncertainty could also be offered guidance on how to deal with uncertainty, by recognizing the impact of uncertainty on oneself, developing more insight into the (maladaptive) strategies one uses to deal with uncertainty, and teaching more adaptive ways to cope with uncertainty (Rodgers et al., 2020).

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Supplemental material

Supplemental material for this article is available online.

Notes

1. In this article, identity-first and person-first terminology will be used interchangeably to acknowledge different perspectives regarding terminology (Robison, 2019).
2. This set of questions was self-developed by the authors. Please contact the authors for more details.

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