

Impact of the COVID-19 Pandemic on Daily Life: Diverse Experiences for Autistic Adults

Jarymke Maljaars^{1, 2, 3}, Eef Gijbels¹, Kris Evers^{1, 2, 3}, Debbie Spain⁴, Freya Rumball^{4, 5},
Francesca Happé⁴, and Ilse Noens^{1, 2}

¹ Parenting and Special Education Research Group, KU Leuven, Belgium

² Leuven Autism Research (LAuRes), KU Leuven, Belgium

³ Child and Adolescent Psychiatry, Z.org UPC KU Leuven, Belgium

⁴ Social, Genetic and Developmental Psychiatry Centre, Institute of Psychiatry, Psychology and Neuroscience, King's College London, UK

⁵ Adult ASD Assessment Service, Oxleas NHS Foundation Trust, UK

E-mail: jarymke.maljaars@kuleuven.be

Abstract

Using a mixed methods design, this study aimed to examine the impact of the COVID-19 pandemic on autistic and non-autistic adults. We conducted an online survey with 196 autistic and 228 non-autistic adults from Belgium, the Netherlands and the United Kingdom focusing on their experiences during the first period of the pandemic. Our results indicate rather diverse experiences within the group of autistic participants across all domains of life. In comparison with non-autistic adults, autistic adults reported less negative impact on their social life and more negative impact on health and support services. In the autism group, stress was mainly related to changing and unclear measures. A wide range of coping strategies were described as helpful in reducing stress during the pandemic.

Key words: autism, adults, COVID-19, pandemic, impact on daily life, perceived stress

In response to the COVID-19 pandemic, countries put in place a range of measures to diminish the transmission of the virus. These included personal measures (e.g., hand hygiene, wearing masks), physical and social distancing measures (e.g., avoiding crowded spaces, working from home), movement measures (e.g., avoiding public transport), and shielding measures (e.g., for people living in residential settings, clinically vulnerable groups) (WHO, 2020). More stringent rules were temporarily applied, often referred to as 'lockdowns', involving the closure of kindergartens, schools, non-essential shops, non-essential businesses, and public places, in combination with stay-at-home orders and travel restrictions. These measures aimed to protect physical health, but also incurred consequences for mental health, and resulted in disruption to social and economic life. Overall, the pandemic has had a negative impact on the wellbeing of

many individuals. Rates of stress, and symptoms of anxiety, depression, and post-traumatic stress disorder, have reportedly been higher in the general population during the COVID-19 pandemic, compared to prior to the pandemic (Xiong et al., 2020). It is conceivable that autistic people are at heightened risk of experiencing adverse effects as a consequence of the pandemic and resultant measures (Ameis et al., 2020; Bal et al., 2021), in particular, when occurring alongside pre-pandemic mental health issues (Yao et al., 2020), for which there is a higher prevalence amongst autistic people (Lai et al., 2019). For example, given that social interactions have changed markedly, and daily routines have become disrupted, the pandemic may have contributed to increased stress and anxiety in autistic people who often rely on routines and find change distressing (Lee, 2020).

During the past year, several studies have examined the impact of the COVID-19 pandemic on autistic individuals. Most studies have been conducted with families with children on the autism spectrum (e.g., Colizzi et al., 2020; Manning et al., 2020), with only a handful (partly) describing the experiences of autistic adults. Studies of adults have mainly focused on the impact of the pandemic on mental health, and reported an increase in stress, anxiety and depressive symptoms (Bal et al., 2021; Bundy et al., 2021; Oomen et al., 2020; Pellicano et al., 2021). A study by Adams and colleagues (2021), compared results of a pre-pandemic survey with a 10-weeks-into-the-pandemic survey in a sample of 275 autistic adults, and showed no clear changes in anxiety and depressive symptoms in general. However, a negative cycle, in particular in women, could be detected: individuals with a higher level of symptoms prior to the pandemic, were more vulnerable to experiencing higher levels of COVID-19-related stress, resulting in an increase in symptoms during the start of the pandemic. A quantitative and qualitative survey study by Oomen and colleagues (2020) included over 1,000 autistic and non-autistic participants. The first theme that emerged from their study was the negative impact of the pandemic on social life. The loss of social contact during the first lockdown resulted in loneliness, social isolation and reduced social support. This finding was replicated in a more in-depth interview study with 144 autistic adults and adolescents and parents of autistic children conducted by Pellicano and colleagues (2021). The second theme to emerge in Oomen et al.'s study was the negative consequences of disruption to routines: the pandemic resulted in many changes in daily activities (Oomen et al., 2020). Difficulties in adjusting to changes at home and in society were also indicated as an important theme in a survey study with 133 autistic adults by Bundy and colleagues (2021). In addition, the previous studies described barriers in access to health and support services and limited perceived support by online services (Bal et al., 2021; Bundy et al., 2021; Oomen et al., 2020). These concerns were echoed

in an online survey study with 37 professionals working with autistic individuals; several concerns about the lack of service provision and possible consequences for mental health were mentioned from the perspective of professionals (Spain et al., 2021). An interview study by Goldfarb and colleagues (2021), with 10 autistic participants, focused more specifically on the impact of the pandemic on work and the advantages and disadvantages of working from home. A positive impact of remote working was described by autistic individuals experiencing social anxiety or hyper-sensitivities to sensory stimuli. Some other beneficial effects of the pandemic lockdown have been noted as well, with a reduction of social pressure deemed the most prominent (Bundy et al., 2021; Oomen et al., 2021).

The current study focuses on the experiences of autistic and non-autistic adults during the first lockdown in Western Europe (Spring 2020) and the period with the first relaxation of COVID-19 measures (Summer 2020) in Belgium, the Netherlands and the United Kingdom. First, we aimed to enhance understanding of autistic individuals' experiences during the COVID-19 pandemic by systematically examining the impact on different life domains (e.g., home/family life, school/work) and stress levels compared to non-autistic individuals. Second, we explored autistic individuals' experiences by analysing their answers to several open questions about positive and negative experiences on different life domains, aspects of the pandemic that have increased stress and factors that have helped them to cope with stress and difficult situations during the pandemic. The resulting qualitative data are used to gain a better understanding of the meaning and implications of the findings from our quantitative data. As our study was designed during the first period of the pandemic, and data were gathered during this unprecedented event and before the emerging research literature on this topic, no specific hypotheses were formulated.

Method

The current study is part of the DiCE study: a longitudinal online survey study focusing on the impact of the COVID-19 pandemic on mental health in autistic and non-autistic adults. The present exploratory study describes data collected at the first time point of this online survey study. Participants were followed up after 3, 6 and 12 months using the same core questionnaires, and those data will be reported elsewhere in due course.

Participants

The study recruited adults (older than 18 years and living in Belgium, the Netherlands or the United Kingdom) with and without autism, fluent in written Dutch or English. Data from 137

individuals were excluded, as they did not complete all the main questionnaires in our first survey ($n = 107$) or did not meet inclusion criteria ($n = 30$). The final sample consisted of 317 Dutch-speaking adults (220 females, 96 males, 1 ‘other’) aged 18-74 years ($M = 41.6$), and 107 English-speaking adults (77 females, 20 males, 10 ‘other’) aged 19-73 years ($M = 41.3$). The Dutch-speaking participants were living in Belgium ($n = 265$), the Netherlands ($n = 50$) and the United Kingdom ($n = 2$), and the English-speaking participants were all living in the United Kingdom ($n = 107$).

Table 1.

Sample characteristics and differences between participants in the autism and non-autism group.

		Autism ($n = 196$)	Non-autism ($n = 228$)	Autism vs non-autism t / χ^2
Gender	male	24%	30%	13.89**
	female	70%	70%	
	other	6%	0%	
Age (years)	M	41.51	41.50	-0.01
	(SD)	(12.28)	(13.23)	
Country of residence	Belgium	54%	69%	9.84**
	The Netherlands	14%	10%	
	United Kingdom	32%	21%	
Living situation	with parents	13%	7%	54.60**
	alone	30%	7%	
	together with partner	20%	25%	
	together with (partner and) children	29%	54%	
	other	8%	7%	
Level of education	low	3%	0%	17.68**
	moderate	26%	13%	
	high	71%	87%	
Occupational status	unemployed	28%	18%	12.29**
	employed (parttime)	34%	31%	
	employed (fulltime)	30%	46%	
	other	8%	5%	
Other mental health diagnosis	no	27%	72%	96.25**
	yes (in the past)	21%	16%	
	yes (currently applicable)	52%	12%	
COVID-19 infection (ever)	no	77%	80%	8.69*
	suspected ^a	22%	16%	
	yes ^b	1%	4%	

Note. * $p < .05$. ** $p < .01$

^a Showed symptoms but not formally tested, or showed symptoms and tested negative.

^b Based on a COVID-19 virus or antibody test.

The 424 participants were divided into two different groups. The autism group ($n = 196$) comprised 161 individuals with a formal diagnosis of autism and 35 individuals self-identifying as having autism. The non-autism group consisted of 228 individuals without an autism diagnosis or self-identification. In both groups, most participants were female (70%). The age

ranged from 18 to 74 years old, and age was equally distributed between both groups. See Table 1 for participant characteristics.

Procedure

The 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 gave informed consent before participating in the study. Our survey was developed in collaboration with a group of autistic adults. The final online Qualtrics survey consisted of several self-report questionnaires. The T1 questionnaire was available between June 20th and September 14th, 2020. Questions were asked both about the time when participants completed the survey (i.e., June-September 2020, referred to as Summer 2020) and retrospectively about the first lockdown (i.e., March-April 2020). During the first lockdown (starting mid-March 2020), the restrictions were comparable in all three countries, including: a stay-at-home order, a ban on all non-essential travel and contact with other people, social distancing mandates in public areas, and shut down of almost all schools, businesses and social venues. The first lockdown was gradually lifted from May in Belgium and the Netherlands, and from June in the UK. In all three countries, the summer (June until August) included months of relaxations of special measures, except for some local lockdown implementations in the North West of England and in Antwerp (Belgium). In July, wearing face masks became compulsory in most indoor spaces and busy outdoor spaces in Belgium and the UK, but not yet in the Netherlands.

Instruments

In the current study, the following components of the survey were used in the analyses.

Background information. Participants were asked to provide information about several personal and contextual factors, such as gender, age, country of residence, living situation, level of education, employment status, autism diagnosis, current and past mental health diagnosis, current physical health, high risk for COVID-19 and COVID-19 infection (summarised in Table 1).

Impact of COVID-19 pandemic. The impact of the COVID-19 pandemic questions focused on five life domains: home/family life, school/work life, leisure/spare time, social life and contact with health/support services. Participants indicated how positively or negatively they experienced the impact of the COVID-19 situation on each domain both during the first lockdown (Spring 2020) and during the past month (Summer 2020) on a five-point scale, from 'very positively' to 'very negatively', or they could also indicate the option was 'not

applicable'. Participants were asked to explain why their experiences were mainly positive or negative in an open question.

Perceived stress, stressful aspects, and coping. The Perceived Stress Scale (PSS-10; Cohen et al., 1983) was used to measure the perception of personal stress during the last month (Summer 2020). The PSS is an instrument consisting of ten items on a five-point scale, ranging from 0 (= never) to 4 (= very often). Total scores between 0 and 13 indicate low levels of stress, 14 to 26 moderate levels of stress and 27 to 40 high levels of stress. The PSS-10 has adequate validity in the general population and good reliability both in the general population and autistic adults specifically (e.g., Cohen & Janicki-Deverts, 2012; Bishop-Fitzpatrick et al., 2017, 2018). The PSS-10 had good internal consistency in the present study (Cronbach's alpha = .85). We also asked whether and why the participants experienced less or more stress during the first lockdown (Spring 2020) compared to their stress level at the time of study participation (Summer 2020). In the final open question, participants were asked what helped them to cope during the COVID-19 pandemic so far and any related stressful situations. We were interested in any individual coping strategies or things others may have done that had helped them cope.

Data analysis

All quantitative analyses were conducted using SPSS. Independent samples *t*-tests and Chi Squares were calculated to investigate group differences in experiences related to the COVID-19 pandemic and perceived stress. In a next step, the responses to open questions of the autistic participants were analysed. This part of the study focuses on the autism group, as only a small minority of non-autistic participants answered the open questions. Those participants were not representative of the non-autism group; participants who answered the open questions tended to be those who reported experiencing current 'long' COVID symptoms. The responses to open questions were analysed using NVivo. We used a thematic analysis approach to become familiar with the data, generate initial codes, search for themes, review themes, define and name themes, and report on the themes (Braun & Clarke, 2006). One of the authors (JM) took the lead in the qualitative coding and discussed the emerging themes with two other authors (EG and KE). All three authors familiarised themselves with 20% of the data and, following that, discussed codes, themes and subthemes until consensus was reached. During the process, the authors critically reflected on similarities and differences between the results and their own experiences during the pandemic, keeping in mind possible projections of the researchers and likely ignorance of unshared experiences (Berger, 2015). Only codes that occurred more than once were assigned to subthemes and themes. To check for stability of (sub)themes, EG

independently double coded 20% of the answers to each question and attributed codes to (sub)themes, resulting in 90% agreement for the coding scheme for impact on different life domains and coping, and 80% for changes in stress. The two open questions regarding the impact of the COVID-19 pandemic on different life domains during the first lockdown (Spring 2020) and Summer 2020 were analysed together, as many participants referred to their answers regarding the first timeframe, when answering the question about the second timeframe. As such, there was a clear overlap in themes between both timeframes.

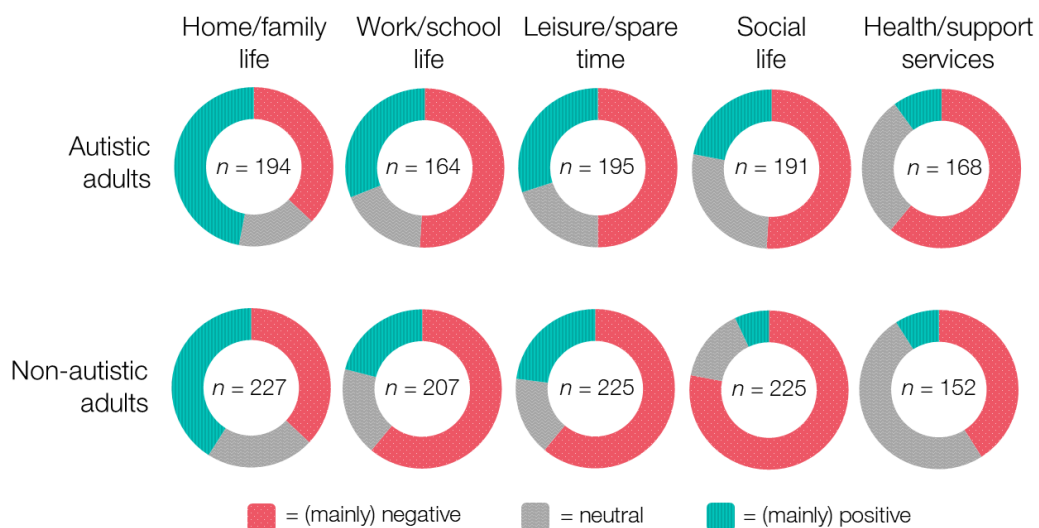
Results

Impact of the COVID-19 Pandemic on Daily Life

Autistic and non-autistic adults reported both positive and negative impacts of the COVID-19 pandemic in all domains during the first lockdown. In general, more negative than positive experiences were indicated by both autistic and non-autistic participants within all the domains, except for home or family life (see Figure 1).

Figure 1.

Experienced impact of the COVID-19 pandemic on different life domains during Spring 2020 (first lockdown) by group: percentages of participants endorsing each response.



Note. Differences in *n* are due to the option 'not applicable' participants could indicate for each domain.

For home or family life more positive than negative experiences were reported by both groups of participants. The impact of the COVID-19 pandemic on participants' social life ($\chi^2_{(2)}$)

= 34.85, $p < .001$) and contact with health/support services ($\chi^2_{(2)} = 19.09$, $p < .001$) was significantly different between the autism and non-autism group. Autistic adults reported significantly more positive and less negative impact on their social life, and a more negative impact on their contact with health/support services compared to the non-autistic adults. No significant differences between the groups were found with regard to the impact on home/family life, school/work life and leisure/spare time. During the Summer of 2020, there was a reduction in the reported negative impact on health and support services in the autism group compared to the first lockdown in Spring 2020 (34 % vs. 61%; $MH = 5.79$, $p < .001$), but also a reduction in the positive impact on the domains of home/family life (28% vs. 47%; $MH = -3.02$, $p = .003$) (see Supplementary Materials for a comparison between scores in Spring 2020 and Summer 2020).

Table 2.

Explanations for positive and negative impact on different domains given by autistic adults.

	Main themes for positive impact:	Main themes for negative impact:
Home/ family life	<ul style="list-style-type: none"> • Spending more time with own family • Quietness and predictability at home • Being able to stay at home alone (more often) 	<ul style="list-style-type: none"> • Feeling lonely or isolated • Too crowded in the house • Difficulties in managing different tasks • Loss of routines • Worries about family and friends
Work/ school life	<ul style="list-style-type: none"> • Preference for working from home/online school • Lower workload 	<ul style="list-style-type: none"> • (Possible) loss of job or income • Difficulties with working from home/online school • Anxiety about going to workplace • Changes at workplace or in tasks allocated • Higher workload
Leisure/ spare time	<ul style="list-style-type: none"> • More time for favourite or relaxing hobbies or activities • More spare time 	<ul style="list-style-type: none"> • Not allowed to do favourite hobbies/(sport) activities • Planned trips or holidays were cancelled • Anxiety about going outside • Difficulties in establishing new routines • Less energy or more difficulties with relaxing • No or less spare time
Social life	<ul style="list-style-type: none"> • Less social demands • More (online) contact with specific people (e.g., neighbour, friend) • Preference for online contacts • More clear social rules • Acceptance 	<ul style="list-style-type: none"> • Missing contact with family and friends • Missing physical contact • Difficulties with (video) calls • Anxiety about meeting people
Health/support services	<ul style="list-style-type: none"> • Preference for, or positive experiences with telehealth • Appointments in person possible 	<ul style="list-style-type: none"> • No or less access to health/support services • Negative experiences with telehealth • Feeling troubled about contacting health services

We asked participants to explain why they had experienced a positive, neutral or negative impact in these domains during the first lockdown (Spring 2020) and Summer 2020; 110 autistic participants (56%) answered these open questions. Some autistic respondents explained that they rated a domain as neutral, because they did not experience big changes compared to their life before the pandemic as, for example, they had always had limited social contact, or their activities did not change. Explanations for positive or negative impact were

diverse among the autistic participants. The main themes in the answers are presented in Table 2.

Home/family life. Several autistic adults described positive experiences within the domain ‘home/family life’ that were related to being at home alone and enjoying spending more time with their partner and/or children at home. Family life was experienced as quieter, more predictable, and more controllable during lockdown.

“My family mostly returned home and I enjoy the fact that we are all together and I know where everyone is and what is going to happen.”

“I’m happy at home with my family. People can’t come round unannounced.”

Some participants, living together with others (e.g., partner, children), had less time and space on their own, because all family members were more often at home together. This caused stress and tension, sometimes resulting in more conflicts. Other participants indicated that they felt lonely or isolated. Other examples of negative experiences were worries about physical or mental health of family members and friends, the loss of routine, and difficulties combining different tasks, such as work, household chores, and/or increased care responsibilities. This was particularly stressful when they had to take care of children or when less support was present, for example, absence of a cleaner or home guidance service.

“The loss of routine and normality is very difficult to handle for me.”

“We all work from home with young kids and I need space as an autistic person. It’s been a bit suffocating.”

Work/school life. Only a few participants reported on their school life, due to the age range of our study, and hence themes are mainly based on reported work experiences. Several autistic adults experienced working from home or online school as positive. They described it as less stressful, as they did not need to travel and, could create a quiet and less overwhelming work environment. Some also felt that online meetings were more efficient or less complicated than in person ones.

“It impacted work positively in that I was made to work from home, my hours weren’t reduced at all and it meant I didn’t have to travel to work through stressful times like rush hour.”

“It feels like a blessing: working for home all days in a quiet environment.” [translated]

Some autistic participants experienced a negative impact in the domain of work, because of uncertainty around employment and a deterioration of their financial situation. Other autistic adults said they found it difficult to work from home or follow classes online. They experienced difficulties with planning and concentration in online meetings and missed contact with colleagues. People who did have to go to their workplace, sometimes had difficulties with changes at their workplace related to COVID-19 measures, changes in tasks or a higher workload. Others reported feeling anxious because they found that not all people followed COVID-19 restrictions completely, or because they did not agree with the way the measures were implemented at work, sometimes resulting in conflicts with colleagues or supervisors.

“I am working from home full time and I struggle a lot to motivate myself to work and manage my own time. I also struggle with calls and video calls and do actually prefer to speak to people face to face. I am worried people will realize I am not working so productively and I might lose my job.”

“There are constantly lots of changes in my workplace, which not all staff are informed about. So, I have no way of keeping up with the constantly changing rules.”

“I have had to work in the office again. Originally our rooms were deemed suitable for only one person and couldn't be used for appointments. Then they put a plastic screen on the desk and said we could have 3 people in the rooms. The window only opens 20 cm and the door has to be closed for privacy. I was terrified (...) and this has made me hate my job.”

Leisure/spare time. Positive experiences expressed by autistic adults related to having more spare time, resulting in more time for favourite or relaxing hobbies or (sport) activities.

“During my spare time, I now had more time to do yoga and to go walking, running and cycling. These activities help me to reduce sensory overstimulation, so I experienced this as a pleasant use of time.” [translated]

“I’ve enjoyed having more leisure time and being able to focus on one of my special interests: gardening. It has kept me focused and motivated.” [translated]

Several reasons were given for the negative impact on leisure or spare time. A lot of autistic adults found it difficult that leisure activities, such as going to the gym, museums and cinema, were temporarily stopped due to the COVID-19 restrictions. In some cases, planned trips to family or holidays were cancelled. Even when people were allowed to go outside (again), several autistic adults did not go, except for essential activities, because they did not feel safe outside, were anxious about catching the virus, or worried about breaking the rules. Some participants experienced difficulties in establishing new routines, especially when they were not allowed to do their favourite activities, sometimes resulting in feelings of boredom. Other participants had no or less spare time or energy for doing these or reported problems finding relaxation in leisure activities.

“I had some out-of-the-house routines that were scuttled, e.g. weekly trips to the local zoo or regular breakfast or coffee places that got me out of the house.”

“Most of my hobbies involved being in public places (e.g., movies, restaurants, shopping). I had to form new hobbies that I could do at home, like playing mobile games and jigsaw puzzles.”

“We’ve been pretty much stuck in place and had major travel plans cancelled repeatedly, which is very hard on my wife in particular.”

Social life. A lot of autistic adults found the reduction of social demands a positive experience. Participants enjoyed feeling no expectations or pressure to go to parties, events, or meet people in person. Other positive experiences were related to an increase in contact with family or friends online or by phone, and more opportunities to socialize online. People appreciated the clearer social rules (e.g., no greetings that involve physical contact) and described feeling more accepted since their social life now resembled the social life of others around them.

“I don’t like socialising and now that we are not able to, it took some of the pressure away I normally feel when having to attend a social event or come up with an excuse to not attend.”

“I definitely had more online social gatherings with people I would never usually talk to that much, which was nice.”

“Social life gives me a double feeling. On the one hand, it’s ‘better’, because social rules are easier. I don’t need to think about whom and when I have to give kisses or shake hands. On the other hand, I really miss my family and physical contact.” [translated]

The negative impact on social life was mainly due to the fact that people were unable to see family and friends (as often as they wanted). Others explicitly mentioned the lack of physical contact. Video calls could not (completely) replace meetings in person and/or were described as exhausting or overstimulating by some autistic adults. Some people indicated that, although restrictions had been loosened, they did not feel safe enough to meet people in person and they were struggling with anxiety about contagion.

“Normally I participate in instrumental music groups at least 4 times a week and these help me to socialize. I haven’t been able to engage with these and have found myself more stressed and lonely.”

“However, missing out on physical social interaction with family has been tough and having to rely on social media platforms to interact with people such as Zoom has been exhausting and overstimulating for me.”

“There is more pressure to go out now that we can. I do want to do these things, but my anxiety leaving the house is higher than ever, so I am struggling to do things.”

Health/support services. Some positive experiences with health or support services were mentioned by autistic adults who were able to have contact in person with services (e.g., GP, psychiatrist, or psychologist) or who had a preference for, or positive experiences with, consultations online, by phone or by e-mail.

“E-consults and video appointments were more accepted, and it meant I didn’t have to expend energy and get myself into pain to go to the GP.”

Most of the participants reported negative experiences in their contacts with support services, because they lost (in part) the support they received before the pandemic or it was

impossible to start support for new requests, at least during the initial phase of the COVID-19 pandemic. Nearly all services cancelled all in person consultations for several months; sometimes it took a considerable time before appointments by video or phone were possible again. Several participants described negative experiences with appointments online or by phone and preferred face-to-face support. Others felt worried about contacting support or health services, because of the pressure on services or anxiety about being offered face-to-face consultations.

“As an autistic person, I am dependent on help from others for certain daily living tasks, such as grocery shopping. Suddenly I wasn’t allowed to go to the supermarket together with my caregiver. Going on my own is not an option for me. Therefore, I became more dependent on others and lost freedom of choice in what to buy.” [translated]

“My psychiatrist appointment moved to phone calls, which is much harder as I usually mostly write what I want to say.”

“I got assistance by phone, but that’s different and not sufficient to help me with all the practical stuff.” [translated]

“Just started telephone cognitive behaviour therapy. I find phone calls really difficult and the first appointment completely wiped me out. Hopefully I won't be so nervous for subsequent appointments, but really frustrating that they don't seem to offer video calls which I find a lot easier.”

“I didn't want to call my GP, I knew they were busy. Waited till I broke a bit before asking for help.”

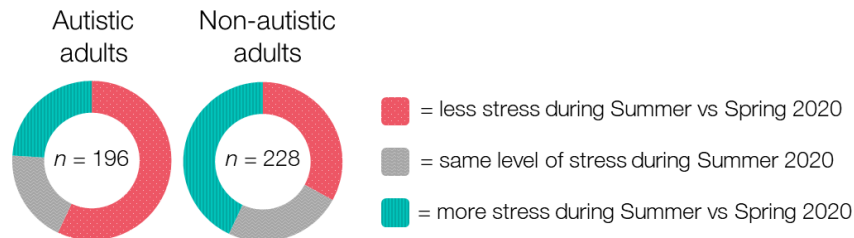
Perceived Stress and Stressful Aspects

The autism group reported significantly more perceived stress compared to the non-autism group as measured by the PSS during Summer 2020 ($t_{(389)} = -9.78, p < .001$). High levels of stress were experienced by 36% of the autistic adults compared to 9% of the non-autistic adults. In both groups, most adults reported moderate levels of stress (57% in the autism and 63% in the non-autism group). We also asked whether they experienced more or less stress during Summer 2020 (when most restrictions were lifted) compared to the first lockdown. More autistic adults (56%) than non-autistic adults (31%) reported experiencing significantly more

stress during Summer than Spring. Fewer autistic (22%) than non-autistic adults (42%) reported less stress during Summer than Spring ($\chi^2_{(2)} = 28.73; p < .001$) (see Figure 2).

Figure 2.

Perceived stress during Summer 2020 compared to Spring 2020 (period of lockdown).



Based on the answers to an open question regarding the explanation for changes in perceived stress, answered by 57 autistic participants (30%), most autistic adults who experienced more stress in the Summer compared to during the lockdown (Spring), cited reasons relating to risks due to relaxation of measures, increasing lack of clarity about the measures, constant changes in measures, a less quiet life, and an uncertain future.

“Things felt more under control during lockdown. Now there are so many risks being taken for reasons I don't think are worth it and it's very anxiety inducing.”

“It's harder now that the rules aren't as strict, plus it's going on for so long. I don't know what the future will be, whether it's the next week, month or year. I have some planned events and a holiday, and I find it hard not knowing if things will change last minute.”

A minority of autistic participants responding to this open question described less stress in Summer versus Spring, mainly because of an increased feeling of familiarity with the whole situation.

“I had less stress in the past month, because of an increased feeling of control, less unexpected things and I feel better prepared for the situation.” [translated]

Specific personal circumstances, such as changes in physical or mental health, financial situation, or employment status, appeared to result in more stress in some cases and less stress in other cases.

Ways to Deal with the Pandemic and to Reduce Stress

The question about what helped participants cope was answered by 148 autistic adults (76%). A range of strategies were mentioned that helped autistic participants to deal with difficult and uncertain situations, and to reduce stress during the first period of the pandemic (see Table 3).

Table 3.

Strategies to reduce stress during the pandemic used by autistic adults.

Main Strategies	Subthemes
Engaging in (new) activities	<ul style="list-style-type: none"> • Seeking other (new) hobbies or activities (e.g., listening to music or podcasts, watching movies, playing games, solving puzzles, building websites) • Expressing yourself creatively (e.g., writing, painting, blogging, journaling, photographing) • Learning something new (e.g., language, musical instrument) • Keeping yourself busy with projects at home (e.g., cleaning, renovating)
Social support	<ul style="list-style-type: none"> • With family, friends or peer groups
Exercise	<ul style="list-style-type: none"> • Physical activities (e.g., walking, running, cycling, dancing, workouts)
Relaxation	<ul style="list-style-type: none"> • Relaxation techniques (e.g., breathing exercises, mindfulness, yoga)
Taking good care of yourself and others	<ul style="list-style-type: none"> • Getting sufficient sleep • Taking time for yourself • Healthy cooking • Helping others (e.g., doing chores for neighbours, family members)
Routines	<ul style="list-style-type: none"> • Maintaining existing routines • Developing new routines • Using a daily or weekly schedule
Following less or no news about pandemic	<ul style="list-style-type: none"> • Following less or no news about the pandemic • Only checking scientific or reliable sources on the pandemic • Limit time on social media
Professional support	<ul style="list-style-type: none"> • Contact with support services: e.g., coach, therapist, psychologist, psychiatrist
Cognitive coping strategies	<ul style="list-style-type: none"> • Seeking distraction • Positive thinking • Putting things into perspective • Humour • Acceptance • Making plans • Learning to deal with uncertainty

There were individual differences in the strategies used by autistic participants to reduce stress, including engaging in various (new) activities, socializing with others, exercising, seeking rest and relaxation, self-care and caring for others, maintaining existing or developing new routines, following less or no news about the pandemic and seeking professional support. Several helpful cognitive coping strategies were mentioned as well, such as positive thinking, putting things into perspective, and humour.

“I have been in constant contact via text messages with my two best friends.”

“I have limited my access to social media, spent more time outdoors exercising and started sewing again.”

“My psychiatrist prescribed additional medication to reduce the restlessness in my head and to sleep better. I made new day and week schedules adjusted to the new situation.” [translated]

“My optimistic mind telling myself there always is a way to solve a problem.”

Discussion

This study aimed to examine the impact of the COVID-19 pandemic on autistic and non-autistic adults in different life domains, as well as perceived stress, and ways to cope with the situation. By using multiple choice and open-ended questions, we gathered both quantitative and qualitative information from our autistic participants. In this way, we tried to obtain an in-depth view of the repercussions of the pandemic and its related measures on the daily lives of autistic adults.

Living during a Pandemic: A Diverse Spectrum of Experiences

We explored the impact of the COVID-19 pandemic on different life domains during the first period of the pandemic (Spring and Summer 2020). Our results indicated that rather diverse, and even opposite, experiences were present in all domains; experiences were neither all positive nor all negative within either group. The experiences of autistic adults were studied in more detail based on their answers to open questions. The qualitative analyses indicate that both personal and contextual factors play a role in how participants experienced the impact of the pandemic. Adults on the autism spectrum constitute a very heterogeneous group and differ, for example, in their need for social interaction, range and impact of hypersensitivities, and the way they deal with changes and uncertainties. All of these factors likely impact the way the autistic adults in our study experienced certain restrictions during the pandemic. Other personal factors, such as physical and mental health, played a major role as well. Contextual factors, such as living situation, financial situation, or occupational status, also affected their experiences.

Home/family life, social life and leisure. Home/family life was the only domain for which more positive than negative experiences were reported by both groups of participants, mainly because of spending more time at home alone or with family. Both regarding family life and leisure, having a less full schedule compared to pre-pandemic times was experienced as less stressful. In relation to social life and leisure, on the one hand, more time to engage in certain interests and hobbies was experienced as relaxing; on the other hand, a lot of changes to certain routines or plans caused stress. Although autistic adults experienced more positive

impact of the pandemic on their social lives compared to our non-autistic adults, experiences were predominantly negative in the autism group as well. The reduction of social demands was mentioned as a positive aspect of the situation, resulting in less social stress and a diminished need to camouflage. Other studies also indicated this as a positive aspect of lockdown (Bundy et al., 2021; Oomen et al., 2021), but suggested that these experiences were transient and overshadowed by negative experiences (Pellicano et al., 2021). In line with previous studies, the lack of sufficient social contact was mentioned as one of the most difficult aspects (Oomen et al., 2021; Pellicano et al., 2021). For most autistic participants, online contact was not an equal substitute for contact in person. Several participants felt lonely and socially isolated, as a result of the measures to mitigate the spread of the virus. The substantial proportion of the autistic participants living alone (much larger than in our non-autism group) could be an explanation for these feelings of loneliness and isolation. Autistic adults reported higher levels of loneliness even before the pandemic (Ee et al., 2019), and these problems may well have been magnified since March 2020. Loneliness has a strong impact on mental health in the general population (Beutel et al., 2017) as well as in autistic individuals (Hedley et al., 2018; Mazurek, 2014).

Work. During the first period of the pandemic, many autistic adults were concerned about losing their job and some were actually made redundant. The COVID-19 pandemic has led to falls in the labour market (Costa Dias et al., 2020). Job insecurity and job loss during the pandemic have been associated with mental health problems (Goldfarb et al., 2021; Wilson et al., 2020). Concerning work, many inequalities were present for autistic people pre-pandemic. Obtaining and maintaining employment is often challenging for autistic individuals (Anderson et al., 2021; Black et al., 2019), and employment rates among autistic adults are low compared to the general population, irrespective of ability (Shattuck et al., 2012). It is still unclear whether economic challenges due to the pandemic will further limit opportunities in the labour market for autistic individuals. In line with Goldfarb and colleagues' (2021) findings, work-from-home experiences were very diverse among autistic individuals in our study. Some participants struggled with concentration, motivation, changes in routines, and the absence of in person interaction with colleagues. Others mainly reported benefits regarding remote working. Several autistic adults said they have asked for a continuation of these arrangements, after the lockdowns/pandemic has ended. Working (part-time) from home might reduce stress during the work day, since individuals are better able to control their sensory environment and avoid a busy commute. Flexibility in work location can be an important facilitator to employment for autistic individuals (Black et al., 2019).

Health care/support. Autistic adults in our study reported significantly more negative impact on their contact with health/support services compared to non-autistic adults. The lack of continuity of support during the first lockdown clearly had an impact resulting in difficulties with organizing daily life and an increase in stress and related mental health problems. Discontinuity of care should clearly be avoided wherever possible. As in previous studies (Bundy et al., 2021; Pellicano et al., 2020), autistic adults' experiences regarding telehealth or e-health were variable: pronounced opponents and proponents were present in our sample. For several autistic adults, support via e-mail, telephone or video calls was less exhausting and lowered the threshold to contact services. Others indicated that these modalities of support could not (completely) replace in person support, in particular with regards to daily life support and mental health issues. A study by Spain and colleagues (2021) showed that, from the perspective of professionals working with autistic individuals, there are also advantages and constraints of telehealth. On the one hand, telehealth can be efficient, but on the other hand, it requires substantial concentration and energy, and can be difficult for certain therapeutic processes. To meet the different needs of autistic adults, support should be offered in a more flexible way. Results underline the potential of blended care – a combination of online and in-person support – to improve accessibility and guarantee continuity, but individual preferences should be taken into account.

Living during a Pandemic: Perceived Stress and Stress Reduction

The arrival of the COVID-19 pandemic disrupted life in many domains, e.g., people needed to stay at home more, social contacts were limited, many outside activities were not allowed anymore. Unpredictable changes in measures and the uncertainty of the situation were experienced as very stressful by autistic and non-autistic adults. In line with previous studies (Pellicano et al., 2020; Oomen et al., 2021), levels of reported stress were higher among autistic individuals compared to non-autistic individuals in our study. However, as baseline information is lacking, we cannot evaluate whether levels of stress were elevated specifically because of the COVID-19 pandemic. On average, our autistic sample reported more stress during a period in which measures were loosened compared to the previous stricter lockdown. Anxiety regarding contagion increased, and many autistic adults had difficulty adjusting their lives to the constantly changing or unclear rules and restrictions, as well as struggling to find new routines at home, for work or school, and leisure time. The uncertainty and disruption of daily life placed a heavy burden on autistic individuals, in particular, in times when less support, both professional and informal, was available (Oomen et al., 2021).

Autistic participants mentioned various activities and strategies that helped to alleviate daily stress during the pandemic, including, for example, seeking social support, seeking distraction or relaxation by engaging in new or favourite activities, physical exercise, or relaxation techniques. Many adults were able to self-manage stress reduction in adequate ways, while others indicated that it would have been helpful to receive more professional support during the pandemic. Finding ways to cope with stress is important, in particular, because elevated levels of stress are linked to anxiety and depressive symptoms (Evers et al., submitted). There are few empirical studies testing the effectiveness of interventions to reduce stress for autistic individuals, but cognitive behaviour therapy (e.g., Wood et al., 2009), mindfulness-based (e.g., Beck et al., 2020) or acceptance and commitment therapy-based interventions (Pahnke et al., 2014) have been found to be effective for reducing stress in this population.

Limitations

First, the generalisability of the results is limited by several characteristics of our sample. The majority of our sample was female, with minimal racial and ethnic diversity. As research design possibilities were limited during the first period of the pandemic, we chose to conduct an online survey to reach as many participants as possible. The disadvantage of this method is that people without access to the internet or without sufficient writing skills were not able to participate. Gathering the experiences of a more population-representative sample of autistic people will be important in the future. Second, as the COVID-19 measures differed from country to country, and from time to time, it is important to acknowledge that the results are based on the situation during the first period of the pandemic (Spring and Summer 2020). The situation and experiences are likely to have changed over time. Therefore, these results should be interpreted in the context of other data collected over the course of the pandemic to assess the long term impact. Third, as we do not have a direct measure of the experienced level of stress during the first three months of the pandemic, we partly relied on retrospective information about participants' experiences during the first lockdown. We have to interpret these results with caution, as memory biases could affect the autism group more than the non-autism group (Crane & Goddard, 2008). Additionally, many of our autistic participants had a mental health diagnosis, such as depression or anxiety disorder – and the autism and non-autism groups differed in this respect. The presence of a mental health diagnosis might influence the recall of positive and negative events; depressed individuals are more prone to a mood-congruent memory bias, resulting in preferential recall of negative information (LeMoult & Gotlib, 2019).

The absence of pre-pandemic data also limits our ability to interpret levels of stress in both groups.

Conclusions

The current study shows the wide variety of experiences and responses of autistic adults to the impact of the first period of the COVID-19 pandemic. In general, autistic people experienced a large amount of stress and responded to this with a range of coping strategies; lessons might be learnt from these to better support autistic people in the future. Before the start of the pandemic, there was limited published research about remote working and telehealth with autistic adults. This study gives some insights into the different possibilities and preferences regarding online work or support among autistic people. Our findings suggest that greater flexibility in future working arrangements and health and social care provision would be helpful, given the diversity of experiences and preferences reported by autistic adults in this study. Furthermore, it suggests a range of possible techniques to cope with stress during uncertain and changeable times, which may reduce risks of developing or exacerbating mental health problems.

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Supplementary Materials

Table S1. Experienced impact of the COVID-19 pandemic on different domains during Spring 2020 (first lockdown).

First lockdown	Home/family life		Work/school life		Leisure/spare time		Social life		Health/support services	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Autism group										
Positive	91	47%	50	31%	59	30%	42	22%	17	10%
Neutral	31	16%	30	18%	39	20%	50	26%	49	29%
Negative	72	37%	84	51%	97	50%	99	52%	102	61%
Non-autism group										
Positive	93	41%	43	21%	52	23%	15	7%	14	9%
Neutral	49	22%	38	18%	35	16%	34	15%	80	53%
Negative	85	37%	126	61%	138	61%	176	78%	58	38%

Table S2. Experienced impact of the COVID-19 pandemic on different domains during Summer 2020 (after first lockdown).

Last month	Home/family life		Work/school life		Leisure/spare time		Social life		Health/support services	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Autism group										
Positive	54	28%	37	22%	51	26%	42	22%	35	21%
Neutral	65	34%	44	27%	59	30%	64	33%	74	45%
Negative	73	38%	85	51%	85	44%	85	45%	57	34%
Non-autism group										
Positive	56	25%	44	21%	56	25%	40	18%	19	12%
Neutral	112	49%	76	37%	75	33%	74	33%	98	63%
Negative	58	26%	86	42%	93	42%	110	49%	38	25%

Table S3. Comparison of impact of the COVID-19 pandemic between Spring 2020 and Summer 2020 based on the Stuart-Maxwell test.

	Home/family life		Work/school life		Leisure/spare time		Social life		Health/support services	
	MH	<i>p</i>	MH	<i>p</i>	MH	<i>p</i>	MH	<i>p</i>	MH	<i>p</i>
Autism group	-3.02	.003	-1.21	.23	0.41	.68	1.12	.26	5.79	<.001
Non-autism group	-0.85	.40	3.46	.001	4.06	<.001	7.30	<.001	3.32	.001