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A qualitative study of autistic adults' quality of life during the COVID-19 pandemic and lockdowns.

Gavin R. Stewart^{1*†} PhD; Marguerite Leoni^{1†}; Rebecca A. Charlton² PhD; Hannah R. Pickard^{1‡} PhD; Francesca Happé^{1‡} PhD

¹ Institute of Psychiatry, Psychology & Neuroscience, King's College London, UK, SE5 8AF

² Department of Psychology, Goldsmiths University of London, UK, SE14 6NW

† Joint first authors

‡ Joint senior authors

* Corresponding author

Dr Gavin R. Stewart (gavin.stewart@kcl.ac.uk); Social Genetic and Developmental Psychiatry Centre; Institute of Psychiatry, Psychology and Neuroscience; King's College London; UK, SE5 8AF

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AUTHOR CONTRIBUTIONS

Authors GRS, RAC, HRP and FH conceived the current study. GRS and HRP designed the online survey and materials. ML coded open text response data, with GRS providing second rater feedback and calibration. GRS, ML, HRP and FH finalised thematic structure of coding. GRS and ML wrote the manuscript, with RAC, HRP and FH reviewing and editing drafts. All authors have read and approved the final manuscript.

CONFLICTS OF INTEREST

None to declare.

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ABSTRACT

Background: Autistic people experience higher rates of most mental health conditions and report more difficulties with change than non-autistic people. As such, the periods of national stay-at-home orders (known in the UK as a 'lockdown') endured since the beginning of the COVID-19 pandemic in March 2020 may have been particularly challenging for autistic people.

Aim: This study explored autistic adults' experience of quality of life and wellbeing during the start of the COVID-19 pandemic (specifically March to August 2020) using open-text responses from an online survey.

Methods: In total, 79 autistic adults from the UK (aged 21-75 years) took part. Participants completed an online survey, including open-text questions on how various factors influencing quality of life, such as social interactions, general health, wellbeing, and sensory experiences, were impacted by the COVID-19 pandemic and the first set of national lockdowns that occurred between March and August 2020.

Results: Thematic analysis created four key themes, each illustrated by several subthemes. These four themes explore 1) health, 2) social changes, 3) support provisions, and 4) adopting new routines. Many participants discussed the impact that the COVID-19 pandemic and first set of national lockdowns had on their health, and expressed concerns regarding the transition out of periods of lockdown, including readjusting to new rules, going back to in-person interactions, and re-acclimatising to high-stimulation sensory environments. However, several participants reported positive experiences of the periods of lockdown, such as reduced commuting, more control over sensory environments, and more time to pursue personal interests and self-care.

Conclusions: These findings highlight the importance of giving autistic individuals the support they need to transition back to "normality" as COVID-19 becomes endemic.

Keywords: Autism, Autistic Adults, COVID-19 Pandemic, Quality of Life, Qualitative

Community Brief

“Why is this an important issue?”

The COVID-19 pandemic and national stay-at-home order (known in the UK as a ‘lockdown’) led to severe disruption and change in people’s lives throughout 2020 and early 2021. However, only a few studies have examined the impact of the lockdowns on autistic people’s wellbeing.

“What was the purpose of this study?”

The abrupt changes caused by the COVID-19 pandemic and lockdowns may have had a more detrimental impact on the lives of autistic people compared to others. This study aimed to explore the impact of the pandemic on the lives of autistic people, and to provide context and descriptions of their experiences.

“What did the researchers do?”

We asked autistic adults a range of open-response questions using an online survey in July/August 2020 to understand how they experienced the COVID-19 pandemic and periods of national lockdown. A total of 79 autistic adults from the UK took part. The questions asked about participants’ health and general wellbeing, their social lives, and sensory differences before (retrospectively) and during the UK national lockdowns that occurred between March and August 2020.

“What were the results of the study?”

Overall, most people felt that the pandemic had a negative impact on their lives. Many felt isolated and lonely due to lockdowns and many expressed feelings of distress and anxiety at

the prospect of returning to normality. However, several participants did report positive aspects of the periods of lockdown, such as having more time for personal interests and practicing self-care, and having to deal with less noise and sensory overload.

“What do these findings add to what was already known?”

To date, much of the research about the impact of the COVID-19 pandemic and lockdowns on autistic peoples' lives has been quantitative (e.g., using scores on questionnaires). This study uses qualitative data (responses to open-ended questions). This study provides important contextualisation of how the pandemic and lockdowns have impacted the lives of autistic people and highlights the need for additional support in the years following the pandemic.

“What are potential weaknesses in the study?”

This study only includes autistic people, so we cannot be sure whether these experiences are unique to autistic people. Additionally, these findings may not be generalisable to the wider autistic population, including those who were unable to participate (e.g., those with learning difficulties).

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

The COVID-19 pandemic and lockdowns are likely to have a long-lasting impact on wellbeing, which may disproportionately impact autistic people. As such, autistic people may need additional, tailored, support as COVID-19 becomes endemic (i.e., no longer a pandemic but part of everyday life, somewhat like seasonal flu). Additionally, lessons may be learned from the pandemic about how society could be adapted to become more inclusive.

INTRODUCTION

In March 2020, the United Kingdom (UK) – as well as many other countries across the world – issued a nationwide stay-at-home order (henceforth referred to as a ‘lockdown’) to address the rapid spread of the COVID-19 pandemic. This led to the abrupt closure of schools and all ‘non-essential’ commercial and recreational services. Many health services also closed to redirect their staff to support patients with COVID-19. During this lockdown, the public were legally obligated to conduct strict social and physical distancing, not to socialise with those outside of their immediate household, to limit outdoor activities (including exercise), and to begin remote working. These measures to address the initial wave of the COVID-19 pandemic lasted approximately 12 weeks. While the prevalence of COVID-19 drastically dropped, the lockdown measures led to widespread disruption of social and economic activity both at the national and individual-level.¹ For many, the rules during the first six months of the COVID-19 pandemic and the first period of national lockdown imposed a forced isolation period and stripped back their access to support services.

Over the past two years, quantitative methods have been predominately used to explore the impact of the COVID-19 pandemic. In a study conducted in spring and summer 2020 by Bal et al. (2021) that involved 396 autistic adults (aged 18-74 years), results indicated that nearly half (45.3%) of the participants endorsed moderate to severe COVID-related psychological distress.² Several factors were associated with greater psychological distress over time, including being female, younger, having a prior diagnosis of a mental health condition, personal experiences of COVID, and being less hopeful for the future. Oomen et al.’s (2021) mixed-methods, multi-country study involving over 1000 participants (aged 18-81 years) reported from their quantitative findings that the pandemic had led to high rates of depression and anxiety for their autistic and non-autistic participants, with this effect being more pronounced in the autistic group.³ Furthermore, the autistic group reported a greater increase in worries about their pets, their work, the availability of food and medication, and their own safety and security. In another study, Davidson, Lodge and Kam (2021) reported

that 72% of their 51 autistic adult participants (who were recruited through a UK autism diagnostic service) reported experiencing a significant deterioration in their mental health over the course of the pandemic.⁴ This deterioration was often attributed to uncertainty over the future and a disruption of normal routine. Bundy et al. (2022) also reported comparable quantitative findings from their mixed-method study with 133 autistic adults (aged 20-72 years).⁵ Many participants had experienced increased feelings of depression, anxiety, and stress throughout the pandemic, although a minority did experience some positive improvements. In a study which explored sleep in a sample of 207 autistic adults (age mean 34 years) by Raynaud et al. (2022), the abrupt change to daily routines caused by the COVID-19 pandemic led to increased circadian rhythm disturbances and poor sleep behaviours.⁶ And finally, in a longitudinal study by Nistico et al. (2022), the researchers reported that their sample of 45 autistic adults from Italy experienced increasing rates of poor mental health and lower perceived wellbeing across the first several months of the pandemic. Nistico et al. suggest that this increase could be attributed to prolonged social distancing and uncertainty for the future.⁷

While several quantitative studies have explored the impact of the COVID-19 pandemic on autistic populations, qualitative research is still sparse. Oomen et al.'s (2021) mixed-methods study reported qualitative findings that their autistic participants found the loss of their routine and social contact the most difficult aspect of the COVID-19 regulations. They also noted that many people experienced some positive aspects to these regulations, specifically that the world had become more 'autism friendly, e.g., through an increase in social cohesion/solidarity and reduced sensory and social overload. Bundy et al.'s (2022) mixed-methods study reported similar qualitative findings to Oomen et al. (2021), with their autistic participants noting difficulties with adjusting to changes in the social world, living with uncertainty, disruptions to self-regulation, and experiencing barriers to fulfilling their basic needs. The findings from these two studies are further supported by a qualitative study conducted between May and June 2020 by Pellicano et al. (2022), where researchers

interviewed autistic adults (n=44, aged 22-69 years) and autistic young people (n=16, aged under 18 years), as well as parents of autistic children (n=84), about their lockdown experiences.⁸ Autistic participants reported feeling released from conventional social challenges, but also a deep sense of social loss, and a deterioration of their mental health. As a result, many participants felt socially isolated and longed for the return of pre-pandemic social interactions. However, these findings differ from the findings of a mixed-methods study by Maljaars et al. (2022) involving 196 autistic adults (aged 18-74) from the UK, Belgium, and the Netherlands.⁹ This study reported that the COVID-19 pandemic had a less negative impact on the autistic adults' social life, but a more negative impact on their health and access to support compared to a non-autistic comparison group. Therefore, it appears that autistic people are impacted in different ways by the pandemic. These experiences require further exploration to understand current and future support needs. Additionally, as the pandemic and lockdowns were a prolonged experience with longstanding public health policy implications, these experiences and support needs are likely to also change over time.

While little is known, as yet, regarding the long-term repercussions of the COVID-19 pandemic and lockdowns, research into prolonged loneliness (i.e., the psychological feeling of being less connected to others) and isolation (i.e., the physical state of little or no social contact) has demonstrated their detrimental effects on mental and physical health.¹⁰⁻¹³ In a systematic review of autistic adults' experience of loneliness, Umagami et al. (2022) highlight that poor mental health, sensory avoidance, and unemployment increase the susceptibility to experiencing loneliness.¹⁴ Additionally, in a meta-analysis of 70 studies, Holt-Lundstad et al. (2015) highlighted that non-autistic people who experience loneliness and social isolation often have poorer health and are at an increased risk of early mortality.¹⁰ As the COVID-19 pandemic and lockdowns also represented an unprecedented period of uncertainty, this could lead to heightened states of depression and anxiety.^{2,15-18}

Some factors (specifically pre-existing mental health conditions and gender) that are linked to the negative impact of the COVID-19 lockdown for autistic people are also commonly

associated with quality of life in autistic adults.¹⁹ Indeed, autistic individuals may be particularly vulnerable, throughout the COVID-19 pandemic, to increased rates of depression, anxiety, other mental health problems, as well as loneliness and isolation.¹³ Autistic individuals experience increased rates of physical and mental health problems, lower quality of life, and disturbed sleep compared to non-autistic individuals, and autistic women often report more symptoms of poor mental health and lower quality of life than autistic men.^{19–24} In a recent meta-analysis of 18 studies, Mason et al. (2020) highlighted that approximately 50% of autistic individuals have ‘poor’ life outcomes, which includes lower employment rates, lower educational achievement, and lacking close relationships.²⁵ Autistic individuals also often have a preference for familiarity and order, resulting in a general tendency to maintain certain patterns of behaviours and a dislike of change.^{26,27} Put together, the characteristics of autism and the current period of forced change and uncertainty caused by the COVID-19 pandemic could lead to autistic people being particularly susceptible to poorer quality of life during and after the pandemic.

The present qualitative study explores the factors influencing the quality of life of autistic adults during the COVID-19 pandemic and initial lockdown. Focusing on factors known to influence quality of life for autistic individuals, we aimed to investigate whether the influence of these factors (e.g., mental and physical health, social and communication skills, experienced loneliness and isolation, social support and access to health care services) had changed over the COVID-19 lockdown. This, in turn, may inform possible interventions to buffer the possible negative impact of the COVID-19 pandemic, helping the transition out of lockdown – and also give an insight into what factors may impact the quality of life of autistic adults in a post-pandemic world.

METHOD

Study Design and Participants

The present study reports cross-sectional data from the COVID-19 Autism Longitudinal Mental Health (CALMH) study collected in July and August 2020, as the UK transitioned out of its first national COVID-19 lockdown that began in March 2020. The CALMH study was an online survey comprising standardised questionnaires about mental health and other experiences, and a series of open-ended questions about how the COVID-19 pandemic influenced participants' quality of life. Here we focus on responses to these open-ended questions. The quantitative data from this survey is currently unpublished. King's College London Ethics Committee granted ethical approval for the CALMH study (PNM Research Ethics Subcommittee, ID: HR-19/20-19250). All participants read an information sheet prior to giving informed consent for their participation. All research conducted adhered to the Declaration of Helsinki. Participants could choose to be entered into a prize draw to win one of twenty £15 Amazon gift vouchers as an incentive for their participation.

All participants in the CALMH study were recruited through our lab group participant database if they had completed a study from our lab group between 2017-2019 and had consented for recontact. All participants who consented for recontact were invited to participate via email. All participants were over the age 18 and provided information about their age, gender, country of residence, education history, employment status, and their current living arrangement. All participants were also asked if they 1) have an autism diagnosis, 2) self-identify as autistic, or 3) consider themselves non-autistic (no diagnosis and do not identify as autistic). Specific data on race/ethnicity and socio-economic status were not recorded.

In total, 96 participants completed the survey. As only 10 non-autistic participants took part, we opted to exclude them and only present the autistic participants' data in this paper.

Additionally, due to differences in Government approach to handling the COVID-19 pandemic, we chose to include only those from the four UK nations, as each devolved Government had comparable lockdown timings and social distancing rules in place, resulting in the exclusion of a further 7 participants. This resulted in a final sample of 79 autistic participants, of which 68 reported having an autism diagnosis, and 11 reported self-identifying as autistic. These two groups were collapsed as self-identified autistic people have seemingly similar experiences to those of diagnosed autistic people²⁸. Preliminary analyses suggested that the inclusion of self-identified participants did not alter the findings. All participant responses were anonymous. See Table 1 for a summary of participant demographic characteristics.

TABLE 1 – DEMOGRAPHICS ABOUT HERE

Materials

This study reports qualitative data collected via free-text to a set of prompted questions in an online survey. During the survey, participants reflected on their quality of life over the COVID-19 pandemic and lockdown. The prompted questions encouraged participants to think about a specific topic, e.g., their 'overall mental health' and to reflect how they would rate this and whether it had changed over the COVID-19 pandemic. Participants provided information about their experiences in a large free entry text box. Participants reported their experiences on 11 prompted topics, specifically: 1) overall well-being, 2) mental health, 3) physical health, 4) cognitive abilities, 5) sensory experiences, 6) social and communication skills, 7) social support, 8) feelings of loneliness, 9) social isolation, 10) experiences of accessing health care, and 11) sleep quality. Some key terms (i.e., cognitive abilities, sensory experiences, social

support, and health care) were briefly defined. A final open question prompt offered the opportunity for participants to provide information about any other key factors that they felt influenced their quality of life over the COVID-19 pandemic and lockdown. Each topic prompt was presented to the participant on an individual page with a large text box for free text entry. See Supplementary Materials 1 for open-ended question prompts.

Community Involvement

No patient and public involvement (PPI) or community involvement occurred in the development of this specific study. PPI interviews were held as part of a previous study from the authors' lab titled the "AgeWellAutism" project. This project aimed to identify key areas that have an influence on the quality of life of autistic individuals. To ensure the questions used in the "AgeWellAutism" project were clear and accessible, 12 autistic people were consulted to refine the content and structure of the final questions used. The same phrasing and structure of these questions were then used in the present CALMH study, although small alterations were made to frame their context around the COVID-19 pandemic (e.g., "has your mental health changed over the past 10 years" became "has your mental health changed over the COVID-19 pandemic").

Positionality

The five authors of this study are non-autistic. All authors have a background in Psychology and Autism research, with experience ranging from being an undergraduate student (ML), to being early career post-doctoral researchers (GRS and HRP), to being senior researchers with 20-30 years' research experience (RAC and FH). All authors share a neurodiversity perspective that recognises that the different way in which autistic people process the world can be challenging in a society designed by and for non-autistic people.

Data Analysis

The dataset included all responses to the open-text questions which were analysed using inductive reflexive thematic analysis, in keeping with Braun and Clarke's six step methodology. To ensure that the lived experiences were interpreted accurately, to avoid the influence of preconceived assumptions about autistic quality of life, we used a 'bottom-up' realist approach.²⁹⁻³¹ As there was significant overlap between the prompted topics asked in this study (e.g., mental health experiences were discussed throughout many of the other topics), each participant's set of free entry responses were viewed as a whole, rather than as individual responses to specific prompts. ML analysed responses using Nvivo (version 12; QSR International, 2018). The authors' created themes at the explicit, semantic level. Participants did not provide feedback or endorsement on the themes and subthemes that were created, as data was stored anonymously.

ML and GRS cleaned the transcripts. Both ML and GRS read through all the transcripts to familiarise themselves with the data, prior to beginning the coding process. ML then initially coded the transcripts. Once all transcripts were coded, ML then reviewed the code list and text, and created initial themes. Each theme and each specific piece of coded text identified by ML was then reviewed and further developed with GRS during three coding discussion meetings. ML and GRS reached full agreement on the coding and themes/subthemes during these discussions. The themes and subthemes were then presented to HRP and FH for further discussion and refinement. Some quotes that were selected to illustrate themes and subthemes were edited for 1) anonymity and 2) for correct spelling/grammar for ease of understanding. The core content and meaning of the quotes are unaltered.

RESULTS

Response rates varied across the 12 questions asked in this study. 71% (n=56) of participants responded to Q1 (wellbeing), 75% (n=59) to Q2 (mental health), 51% (n=56) to Q3 (physical health), 38% (n=30) to Q4 (cognitive abilities), 50% (n=39) to Q5 (sensory experiences), 57% (n=45) to Q6 (social and communication skills), 52% (n=41) to Q7 (social support), 58% (n=45) to Q8 (loneliness), 52% (n=41) to Q9 (social isolation), 44% (n=34) to Q10 (healthcare access), 48% (n=37) to Q11 (sleep quality), and 92% (n=72) to Q12 (any other factors). On average, participants provided 38-word responses to each answered question (range=2-335 words).

The coding process resulted in the creation of several themes and subthemes. Theme 1 explores the impact of the first COVID-19 pandemic lockdown on health (illustrative quotes in Table 2), Theme 2 explores how socialisation changed (Table 3), Theme 3 explored how formal and informal support needs and provisions changed (Table 3), and Theme 4 explored the challenges of adapting to new routines and environments (Table 4).

Theme 1: The impact of the first COVID-19 pandemic lockdown on health

Subtheme 1A: The widespread impact of mental health. Many participants mentioned how their health was impacted in various ways by the COVID-19 pandemic and first period of national lockdown. While a small number of participants felt their mental health improved during the early stages of the first lockdown (due to life being quieter, set to a slower pace; “*I wish [social distancing, working from home] would last forever*”), most felt their mental health was progressively declining; “*I have found my depression worsen over the pandemic and I’m feeling hopeless every day*”. This decline was attributed to low mood and the worsening of their pre-existing mental health conditions.

Subtheme 1B: A growing sense of anxiety. Several participants mentioned that their lockdown experiences were “tinted by persistent feelings of anxiety”. This sense of anxiety was described by some as being ‘contagious’; “*anxiety in the population is ‘catching’.*”. This persistent anxiety manifested in many forms; some participants discussed anxiety about them or their loved ones contracting COVID-19, others expressed anxiety about the behaviour of others, such as not adhering to face-mask regulations or breaking social distancing rules. Anxiety about the uncertainty of the future was also common.

Subtheme 1C: Worrying about the impact of restrictions. The rules and regulations of lockdown were also commonly discussed as influences on mental health. Participants described feeling trapped at home and unable to alleviate their stresses due to ambiguity of lockdown rules. Some described no longer having the opportunity to use any of their regular or habitual coping mechanisms (e.g., going swimming, meeting friends) and struggling to find alternatives; “*I have been unable to use distraction techniques that I would have used to raise my mood when it begins to dip, so my mental health has become worse.*”. Additionally, participants worried about how stable their employment will be once the furlough scheme had ended, and how their professional work environment would need to be adapted after lockdown to account for new restrictions in place.

Subtheme 1D: Difficulties with camouflaging their mental health problems. Several participants also discussed concerns regarding camouflaging their current mental health problems, with one person describing their depression ‘seeping through in inappropriate ways’ when socialising with people. Participants also highlighted that their mental state, and inability to effectively camouflage, was also impacting their ability to socialise; “*It’s hard to hide how I feel.*”.

Subtheme 1E: Lifestyle changes leading to changes in physical health and general fitness. Many participants discussed how their physical health was being positively influenced by the lockdown. These participants discussed how, with the greater time flexibility offered by the lockdown, they were able to adopt healthier lifestyle behaviours; *“I was able to lose some weight and I’ve been doing a lot more exercise. I feel great.”*. These changes to lifestyle were due to the availability of time to take care of themselves (e.g., no longer commuting to work, not having any in-person obligations), but also realising the importance of staying fit to reduce the risks of health complications in case of illness. However, many participants also noted the impact of their declining mental health was also impacting their physical health; *“I have been overeating through anxiety/boredom and not taking my usual amount of exercise which has impacted my general health.”*. Several participants mentioned that they lacked motivation to exercise, and that they were experiencing high levels of anxiety about leaving their homes to exercise for fear of contracting the virus. A small number of participants also reported that this heightened anxiety led them to stress eat.

TABLE 2 – THEME 1 QUOTES ABOUT HERE

Theme 2: Social Changes

Subtheme 2A: Less pressure to socialise. Some participants described the inability to have face-to-face social interactions with others as a relief, since they no longer felt obliged to socialise and meet friends or colleagues from work. One participant noted ‘feeling comforted’ by the idea that everyone was in a similar situation during lockdown; *“Nobody is making me feel like I should be more sociable.”*. Benefits to the lockdown were also discussed, such as ‘simplifying’ life by reducing social contact to manageable levels; *“The lockdown has simplified*

my life, given it a slower pace, made it calmer, given me more time to keep on top of things, and reduced my socialising to a level I can cope better with.”.

Subtheme 2B: Experiences of social isolation and loneliness. Being isolated and feeling lonely were very commonly reported experiences for most participants. Many discussed the paradoxical sensation of being ‘around other people’ while still feeling psychologically ‘isolated’; *“I like being on my own and having space, but I feel isolated sometimes in a crowd.”.* Others discussed that their sense of isolation was not from being physically distant from others, but that they could no longer access their daily routine, e.g., grocery shopping. Those who were shielding also felt the burden of being unable to see friends and family. And many felt that their worries of being exposed to the virus created a barrier to them leaving their homes; *“Although I am a complete introvert, being isolated so much has been very unhealthy for me, and I find it hard to leave the house at all now.”.*

Subtheme 2C: Using digital communication tools to remain socially integrated. Many participants noted having digital interactions for the first time, such as using video call platforms to meet with friends, family, and colleagues during the lockdown period. Several participants expressed their concerns about adapting their social communication skills developed in physical interactions, to new mediums of contact, such as online interactions; *“I’m having to learn how to communicate virtually now. I long for a time when I can meet my friends physically again.”.* These online interactions involved learning new social etiquette, such as when to speak in virtual group meetings. This often led to a sense of social anxiety. Several participants also observed that they found using this type of software beneficial, as it created a less anxiety-inducing environment than in-person meetings, allowing them to camouflage less since everyone was adapting to digital interactions, and they could be in greater control of their sensory environment during the meeting; *“I find using online meetings*

less stressful. I feel less anxiety in video calls with my co-workers compared to in-person meetings. I also think the camouflaging needs are much simpler.”. Some participants expressed hope that digital interactions will become the norm in the future.

Subtheme 2D: Becoming out of practice. Several participants expressed their concerns about becoming out of practice with in-person social communication and feeling that their communication skills had deteriorated due to a lack of practice during lockdown; *“I go out less so I practice less. When I do go out, I find interacting with people difficult and I am much more silent in public than I used to be.”*. Concerns were also voiced about communicating with face-masks on, due to the reliance on reading lips and facial expressions.

TABLE 3 – THEME 2 AND 3 QUOTES ABOUT HERE

Theme 3: Changes to formal and informal support provisions

Subtheme 3A: Dealing with changes to service and new policies. Cancelled non-emergency services and changes to care in the community were also commonly discussed. Several participants mentioned long waiting lists for clinic appointments, as well as being unable to book appointments with their GP and other services due to the lockdown. Additionally, many felt that their pre-existing community care changed due to the lockdowns, and these changes did not cater to their needs, sometimes resulting in termination of support;

“I was given the option of continuing my counselling support by phone or to be discharged. I didn't feel able to do it by phone, so I had no choice but to be discharged.”. Many participants also commented on the lack of clarity regarding accessing remote healthcare for the first time, or how their past and ongoing support would transition in the future, if at all, to virtual telehealth. For those who did have telehealth appointments, most found the services problematic for various reasons, including being anxiety-inducing and exacerbating their communication difficulties. Some opted to stop support due to this transition to telehealth. However, a few participants did report finding telehealth more beneficial than in-person support, as they did not have to travel and were more in control of their sensory environment at home.

Subtheme 3B: Opting to cancel appointments. Difficulties with accessing medical support during lockdown were reported. Several participants mentioned that they had chosen to cancel appointments as they did not feel comfortable visiting a hospital for fear of exposure to COVID or were unable to communicate easily with their healthcare practitioner while wearing a face-mask; *“I can't speak to my GP in their face mask. I feel uncomfortable going in, so I won't go.”*

Subtheme 3C: Reaching out to family and friends. The lockdown and pandemic were also found to impact the support that participants received from friends and family. Very few participants said that they were fully independent and required no support from others. Most participants reported that their main source of support was their friends and family, due to lockdown restrictions; *“It feels like the world has shut down. The new rules and policies that have been put in place mean that my formal support has disappeared. But I have my family around me and take comfort in us all being in this together.”*. However, some participants felt that the shift of support provision to their family and friends created a source of tension and

triggered a sense of being a burden; *“I’ve become too dependent on wife since the lockdowns have started, and unfair on her.”*. Some also noted the difficulties of discussing their worries with family or friends, as opposed to professionals; *“I am very bad at asking for help outside a clinical structured setting like therapy.”*.

Theme 4: Adopting new routines and adapting to new environments

Subtheme 4A: Change in routine altering sleep patterns and behaviours. Changes to sleep quality and duration were commonly mentioned by participants. Several participants noted that two main factors were influencing their sleep: the difficulty of keeping a routine, and the impact of anxiety. A small number of participants also described having difficulties with keeping a work and personal life balance; some participants found their work/home life blurring together and others began daytime napping. This disruption in sleep cycle was sometimes attributed to not feeling tired at appropriate times (i.e., at night), and having a more flexible sleep/wake time as they no longer had to commute to work; *“I’ve always struggled to sleep at night unless I am incredibly fatigued. It is even harder now as I no longer have to leave for the office. Staying up late has become the norm and I no longer bother to wake up in the morning.”*.

Subtheme 4B: Disruptions leading to problems with cognitive function. Disruptions to daily routines, lack of social contact, and poor sleep were also discussed as impacting general cognitive functioning, such as decreasing concentration; *“My memory and concentration are worse. Sleep problems and stress make me less able to function. It is harder for me to mask my autism and appear level-headed and competent as I am constantly worried and distracted.”*. Difficulties dealing with intrusive memories, engaging in masking behaviours, and general planning (e.g., having to bulk buy groceries) were also mentioned. Difficulties with paying attention were often attributed to the idea of ‘over-stimulation’ from incessant news

reports on the progress of the pandemic; *“I have difficulty concentrating on my studies as I have been constantly distracted and upset by bad news from around the world.”*

Subtheme 4C: Time to reflect and the importance of self-care. A small number of participants discussed how they used the time that lockdown provided, giving them space to reflect on their personal experiences; *“Lockdown has allowed me time/headspace to process more.”* This was described as having both positive and negative implications. Some participants also mentioned that they have found they now have the time to adopt new routines that have been vital for their well-being, including spending time on self-care and hobbies; *“I’ve also come to really appreciate the importance of self-care and hobbies which for me include, singing, painting, and creative writing, and dancing.”* However, several people found their self-care had been disrupted; this was attributed to their sense of time and their general cognitive functioning being impacted by the pandemic.

Subtheme 4D: Controlling sensory environments. Sensory experiences were reported to have a positive impact on quality of life during lockdown. Many participants discussed being greatly relieved to no longer have to commute and go to offices with bright lights, loud and overcrowded workspaces, and people talking over one another. They appreciated having greater control over their own, safe, sensory environment, and for some, this reduced sensory input allowed improvement in their mental health and the quality of their social interactions; *“I am able to tolerate others better now because of the reduced exposure to the outside stimulus.”* A small number of participants described finding social distancing measures beneficial to their sensory experiences when out in public, allowing them greater personal space and ease of movement; *“I like the personal space that comes with social distancing.”*

Subtheme 4E: Concerns about adjusting back to previous sensory environments.

Several participants expressed a sense of dread over coming out of lockdown. This was attributed to a loss of habituation to loud noises, crowded areas, and bright lights. Worries about feeling overwhelmed when going back to what life was like before the pandemic were commonly voiced; *“Because I have not had the ability to consistently confront sensory issues to de-sensitise, when I did attempt a trip to the garden centre, which I would usually have been able to accommodate, I suffered a severe panic attack and sensory overload.”*

TABLE 4 – THEME 4 QUOTES ABOUT HERE

DISCUSSION

This study documents autistic adults' views about the influence of the COVID-19 pandemic on their quality of life. Based on the prompts given to the participants, four key themes were created: the first relating to how health was impacted by the lockdown, the second focusing on participant's social changes, the third looking at how support provisions changed, and the fourth on adopting new routines. In line with the previous literature, although several participants reported having had a positive experience of lockdown linked to improved mental health, almost all participants commented on their deteriorating overall mental health throughout lockdown and in anticipation of a return to a pre-pandemic life.⁵ These findings suggest that autistic people may need additional support throughout the pandemic, as well as after the pandemic comes to an end.

The first key theme created was the impact of the COVID-19 pandemic lockdown on health. Overall, participants told us their mental health worsened during the early stages of the pandemic, including when restrictions were lifted and people began transitioning out of the first lockdown. For some this was described as a worsening of their pre-existing mental health problems, and others the emergence of low mood and anxiety. These findings align with those of the National Autistic Society (2020) that 9 out of 10 autistic people were concerned about their mental health during the course of lockdown, and with the previous literature, e.g., Davidson et al. (2021) who reported 72% of their autistic sample experienced deteriorations to their mental health during the pandemic.^{4 32} It is important to bear in mind that autistic adults are at greater risk of having psychiatric difficulties, in particular anxiety and depression, even without a global pandemic.²¹

A common experience mentioned by the participants was a persistent feeling of anxiety, which was attributed to external factors, such as ongoing media coverage and the number of

COVID-19 cases and deaths, but also to internal factors such as participants' fear of themselves or their families contracting the virus. Another external source of anxiety mentioned was seeing other members of society not respecting social-distancing and healthcare measures. This increased anxiety (described as either newly emerging or as a worsening of pre-existing symptoms) was seemingly exacerbated by difficulties accessing previous coping mechanisms such as going to the gym, and struggling to find "lockdown-friendly" alternatives. More importantly, and in line with similar COVID impact studies, participants were also anxious about the stability of their employment and how their work environments would evolve and adapt after lockdown.^{3,5,33} The high levels of anxiety relating to employment is unsurprising in light of Mason et al.'s (2018) study highlighting the greater importance of employment as a predictor of quality of life for autistic versus non-autistic people.¹⁹ It is important to bear in mind that poor employment rates and difficulty securing work were evident for autistic people even prior to the current pandemic.^{34,35} However, as noted in Oomen et al (2021) and Bundy et al.'s (2022) studies, a few participants did notice a positive impact of lockdown on their mental health, with the alleviation of daily stressors such as commuting or noisy and bright environments, using this quieter pace of life to engage in mindfulness.⁵

With regards to physical health, several participants mentioned that the lockdown period had a positive impact on their general fitness. Some participants used the opportunity of a different work-life balance and more time to adopt a healthier lifestyle and to exercise more, realising the importance of being physically fit in light of the health profiles of the most severe COVID-19 cases. However, other participants noted that their lack of motivation and increased stress caused by the COVID-19 pandemic and periods of lockdown impeded their ability to continue with their normal exercise routine and diet, with some finding their physical health had deteriorated as a result.

The second key theme created related to social changes. A few participants mentioned not noticing any changes in the amount of social interactions they had, but most participants reported having felt lonely and isolated during the lockdown periods. Our findings fit with the qualitative findings reported by Bundy et al. (2022) and Pellicano et al. (2022) who reported that many of their autistic participants felt isolated from wider society during the pandemic.⁵⁹ Pellicano et al. (2022) noted that their participants experienced a great sense of loss for their social lives, highlighting the importance of social networks.⁸ Additionally, these findings are in line with past research in which autistic people have been found to be at greater risk of being socially isolated compared to non-autistic people prior to the pandemic.^{36,37} Some participants also discussed the paradox of being physically with others but still feeling isolated, with a minority feeling comforted by the idea that others were now in the same situation of isolation as they were usually.

As in Oomen et al.'s (2021) mixed method study, some of our participants reported feeling relieved because the pressure to engage in social interactions was removed during lockdown.³ The use of virtual communication tools also helped alleviate certain social pressures, including the need to camouflage. However, many participants also noted that virtual social interactions did not fully replace the experience of a physical meeting. A few participants mentioned missing in-person interactions but also fearing their return, due to a lack of social practice during lockdown. These findings fit with Jaswal and Akhtar's (2019) argument that some autistic individuals are just as socially motivated and eager to socialise as non-autistic individuals.³⁸ The benefits of these virtual platforms, highlighted by participants, reveal the importance of the context and environment in facilitating the ease of social engagement by autistic individuals.³⁸

The third key theme explored changes to formal and informal support provisions. Remote and group appointments often replaced face-to-face appointments, resulting in some participants choosing to cancel appointments and refusing to seek help altogether. The COVID-19

pandemic appears to have exacerbated pre-existing difficulties of healthcare access; autistic individuals already expressed difficulties communicating with healthcare professionals and accessing services prior to lockdown.³⁹⁻⁴¹ Additionally, many participants mentioned that they had experienced difficulties with accessing their existing health care support during the lockdowns, resulting in a lack of formalised support. Some participants mentioned that they felt they had to shift to relying on informal and personal networks for their support needs, such as family and friends – a change also reported by Bundy et al. (2022) and Pellicano et al. (2022).⁸ Mason et al. (2018) highlight the importance of knowing support (e.g., someone to talk to) is available if needed, for autistic adults' quality of life.¹⁹

The fourth key theme created related to the need to adopt new routines and to adjust to new environments. The forced and abrupt change of routine was one of the main factors that participants said influenced their general cognitive functioning. These disruptions to routine were seen as leading to difficulty sleeping, in turn impacting concentration and attention, everyday memory, and daily life tasks such as self-care. Some participants also linked sleep and cognitive difficulties (e.g., with planning large shopping lists, or having the cognitive flexibility to adopt a new routine) to heightened anxiety levels and the absence of any perceived obligation to get up and go to work. Once again, these qualitative findings further contextualise the experiences of autistic people reported in other COVID impact studies; Bundy et al. (2022), Pellicano et al. (2022), and Maljaars et al. (2022) report that their participants experienced many barriers to fulfilling their basic needs during the pandemic, and Oomen et al. (2021) found that their participants struggled with adapting to a loss of routine and structure in their lives.^{3, 7-9}

Regarding sensory experiences, most participants noticed an improvement in their sensory environment, as they were no longer having to commute or work in noisy, bright and crowded places. This also emerged in Bundy et al.'s (2022) study, in which some participants reported having better sensory regulation because they were in greater control of their

environments.⁵ However, our participants also reported fearing readjusting back to “normality” due to having been de-habituated over the lockdown period. Thus, the transition from lockdown to a post-pandemic society could result in additional stressors caused by difficulties reacclimatising to sensory environments, which could have a serious impact on autistic people’s quality of life.

Limitations

The main strength of this study is the qualitative data extracted from a demographically varied population of autistic adults across the adult lifespan. The prompts used encouraged the participants to reflect on different aspects of their lives, and to share their experiences of how the COVID-19 pandemic has impacted them. However, there are three main limitations to this study: 1) the generalisability of our findings, 2) the lack of a comparison group, and 3) how this particular study sits in the longer timeline. First, as with many projects using surveys to gain an insight into the experience of autistic individuals, our study only targeted a certain portion of the population, therefore our findings may not be generalisable to the broader autistic population in the UK or elsewhere.⁴² Additionally, our online self-report survey targeted community dwelling individuals able to read and type responses on computer, so it is unlikely to include individuals with language or intellectual disabilities. Similarly, although participants could choose the length of their answers (or whether to respond to questions at all), there were many open-text responses required, possibly overwhelming some participants. As such, future studies could implement options to make similar surveys more accessible to a larger portion of the autistic population, such as audio recording responses rather than typing. Second, since we did not include a comparison non-autistic group, we cannot infer whether our findings are unique to autistic people, or that the impact of lockdown on daily life is greater for autistic people than for others. Additionally, we did not ask participants to report whether they experienced any pre-existing health conditions that may have influenced their experiences during the COVID-19 pandemic and periods of lockdown. Finally, the current

study only looked at cross-sectional data collected in July and August 2020. It will be important to use longitudinal methods to study the evolution of factors influencing quality of life as the world progresses through the COVID-19 pandemic. Additionally, only by studying the long-term impact, years after the COVID-19 pandemic, will we begin to understand the true extent of the pandemic's impact on quality of life, including resilience, or possible cases of post-traumatic stress disorder (PTSD), for example.¹⁷

Future research

Based on the results discussed above, it is vital to investigate the long-term impact of the lockdown periods and the pandemic on autistic people, particularly as society creates a 'new normal' model of work and living. Due to the long-term uncertainty caused by the pandemic, autistic people may be disproportionately impacted now and in the future. Rumball et al. (2021) suggest that autistic individuals are at greater risk of developing PTSD for events that might not be interpreted as traumatic by non-autistic people.⁴³ Rates of PTSD related to the pandemic are as yet unknown, but high rates of trauma and PTSD symptoms have been found in autistic/high autistic trait populations prior to the pandemic.^{24,43,44} Thus, gathering data on PTSD post-pandemic in autistic and non-autistic groups will be informative. Future research should attempt to identify possible pre-emptive measures/interventions to act as a buffer to protect the mental health of autistic individuals in case of future unprecedented events. Finally, steps should be taken by researchers to improve the accessibility of their research (e.g., by offering alternate ways of completing surveys, modified survey lengths, etc.), to ensure that as many people can access and contribute their experiences as possible.

Conclusion

The current study sheds light on the factors autistic adults feel have influenced their quality of life during the COVID-19 pandemic and early periods of lockdown in the UK. Despite a

substantial minority of comments revealing a positive experience of lockdown due to a quieter and calmer environment/pace of life, the majority of participants reported a negative impact of lockdown on their overall wellbeing and quality of life. Concerns mainly focused on transitioning out of lockdown, adjusting to new rules, going back to in-person interactions and re-acclimatising to high-stimulation sensory environments. As the pandemic wanes and restrictions ease, these findings highlight the importance of giving autistic individuals the support they want and need as we transition to a post-pandemic way of life.

REFERENCE LIST

1. Han E, Tan MMJ, Turk E, et al. Lessons learnt from easing COVID-19 restrictions: an analysis of countries and regions in Asia Pacific and Europe. *The Lancet*. 2020;396(10261):1525-1534. doi:10.1016/S0140-6736(20)32007-9
2. Bal VH, Wilkinson E, White LC, et al. Early Pandemic Experiences of Autistic Adults: Predictors of Psychological Distress. *Autism Research*. 2021;14(6):1209-1219. doi:10.1002/aur.2480
3. Oomen D, Nijhof AD, Wiersema JR. The psychological impact of the COVID-19 pandemic on adults with autism: a survey study across three countries. *Mol Autism*. 2021;12(1). doi:10.1186/s13229-021-00424-y
4. Davidson CJ, Lodge K, Kam A. The impact of the COVID-19 pandemic on autistic adults – a survey. *Advances in Autism*. 2021;7(4):311-321. doi:10.1108/AIA-10-2020-0057
5. Bundy R, Mandy W, Crane L, et al. The impact of early stages of COVID-19 on the mental health of autistic adults in the United Kingdom: A longitudinal mixed-methods study. *Autism*. Published online 2022. doi:10.1177/13623613211065543
6. Reynaud E, Pottelette J, Rabot J, et al. Differential effects of COVID-related lockdown on sleep–wake rhythms in adults with autism spectrum disorder compared to the general population. *Autism Research*. 2022;15(5):945-956. doi:10.1002/aur.2692
7. Nisticò V, Fior G, Faggioli R, Priori A, Gambini O, Demartini B. The Psychological Impact of COVID-19 among a Sample of Italian Adults with High-Functioning Autism Spectrum Disorder: A Follow-Up Study. *Healthcare (Switzerland)*. 2022;10(5). doi:10.3390/healthcare10050782
8. Pellicano E, Brett S, den Houting J, et al. COVID-19, social isolation and the mental health of autistic people and their families: A qualitative study. *Autism*. 2022;26(4):914-927. doi:10.1177/13623613211035936
9. Maljaars J, Gijbels E, Evers K, et al. Impact of the COVID-19 Pandemic on Daily Life: Diverse Experiences for Autistic Adults. *J Autism Dev Disord*. Published online 2022. doi:10.1007/s10803-022-05437-x
10. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review. *Perspectives on Psychological Science*. 2015;10(2):227-237. doi:10.1177/1745691614568352
11. Serafini G, Parmigiani B, Amerio A, Aguglia A, Sher L, Amore M. The psychological impact of COVID-19 on the mental health in the general population. *QJM*. 2020;113(8):229-235. doi:10.1093/qjmed/hcaa201
12. Mazza C, Ricci E, Biondi S, et al. A nationwide survey of psychological distress among Italian people during the COVID-19 pandemic: Immediate psychological responses and associated factors. *Int J Environ Res Public Health*. 2020;17(9). doi:10.3390/ijerph17093165
13. Holmes EA, O'Connor RC, Perry VH, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *Lancet Psychiatry*. 2020;7(6):547-560. doi:10.1016/S2215-0366(20)30168-1

14. Umagami K, Remington A, Lloyd-Evans B, Davies J, Crane L. Loneliness in autistic adults: A systematic review. *Autism*. Published online 2022. doi:10.1177/13623613221077721
15. Vindegaard N, Benros ME. COVID-19 pandemic and mental health consequences: Systematic review of the current evidence. *Brain Behav Immun*. 2020;89:531-542. doi:10.1016/j.bbi.2020.05.048
16. Fancourt D, Steptoe A, Bu F. Trajectories of anxiety and depressive symptoms during enforced isolation due to COVID-19: longitudinal analyses of 36,520 adults in England. *medRxiv*. Published online 2020. doi:10.1101/2020.06.03.20120923
17. Cooke JE, Eirich R, Racine N, Madigan S. Prevalence of posttraumatic and general psychological stress during COVID-19: A rapid review and meta-analysis. *Psychiatry Res*. 2020;292. doi:10.1016/j.psychres.2020.113347
18. Salari N, Hosseini-Far A, Jalali R, et al. Prevalence of stress, anxiety, depression among the general population during the COVID-19 pandemic: A systematic review and meta-analysis. *Global Health*. 2020;16(1). doi:10.1186/s12992-020-00589-w
19. Mason D, McConachie H, Garland D, Petrou A, Rodgers J, Parr JR. Predictors of quality of life for autistic adults. *Autism Research*. Published online 2018:1138-1147. doi:10.1002/aur.1965
20. Croen LA, Zerbo O, Qian Y, et al. The health status of adults on the autism spectrum. *Autism*. 2015;19(7):814-823. doi:10.1177/1362361315577517
21. Lai MC, Kasseh C, Besney R, et al. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *Lancet Psychiatry*. 2019;6(10):819-829. doi:10.1016/S2215-0366(19)30289-5
22. Stewart GR, Corbett A, Ballard C, et al. The Mental and Physical Health Profiles of Older Adults Who Endorse Elevated Autistic Traits. *The Journals of Gerontology: Series B*. Published online August 5, 2020. doi:10.1093/geronb/gbaa112
23. Stewart GR, Corbett A, Ballard C, et al. Sleep problems and mental health difficulties in older adults who endorse high autistic traits. *Res Autism Spectr Disord*. 2020;77(July):101633. doi:10.1016/j.rasd.2020.101633
24. Stewart GR, Corbett A, Ballard C, et al. Traumatic life experiences and post-traumatic stress symptoms in middle-aged and older adults with and without autistic traits. *Int J Geriatr Psychiatry*. 2021;37(2). doi:10.1002/gps.5669
25. Mason D, Capp SJ, Stewart GR, et al. A Meta-analysis of Outcome Studies of Autistic Adults: Quantifying Effect Size, Quality, and Meta-regression. *J Autism Dev Disord*. 2020;(0123456789). doi:10.1007/s10803-020-04763-2
26. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*. American Psychiatric Publishing, Inc; 2013. doi:10.1176/appi.books.9780890425596.744053
27. Joyce C, Honey E, Leekam SR, Barrett SL, Rodgers J. Anxiety, Intolerance of Uncertainty and Restricted and Repetitive Behaviour: Insights Directly from Young People with ASD. *J Autism Dev Disord*. 2017;47(12):3789-3802. doi:10.1007/s10803-017-3027-2

28. McDonald TAM. Autism Identity and the “Lost Generation”: Structural Validation of the Autism Spectrum Identity Scale and Comparison of Diagnosed and Self-Diagnosed Adults on the Autism Spectrum. *Autism in Adulthood*. 2020;2(1):13-23. doi:10.1089/aut.2019.0069
29. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
30. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health*. 2019;00(00):1-16. doi:10.1080/2159676X.2019.1704846
31. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589-597. doi:10.1080/2159676X.2019.1628806
32. National Autistic Society. *The Impact of Coronavirus on Autistic People and Their Families in the UK*.; 2020. <https://s4.chorus-mk.thirdlight.com/file/1573224908/63117952292/width=-1/height=-1/format=-1/fit=scale/t=444295/e=never/k=da5c189a/LeftStrandedReport.pdf>
33. Pellicano L, Brett S, Heyworth M, et al. “I Want to See My Friends” *The Everyday Experiences of Autistic People and Their Families during COVID-19*.; 2020. <https://www.sydney.edu.au/sydney-policy-lab/news-and-analysis/news-commentary/the-everyday-experiences-of-autistic-people-and-their-families-d.html>
34. Chen MH, Wei HT, Chen LC, et al. Autistic spectrum disorder, attention deficit hyperactivity disorder, and psychiatric comorbidities: A nationwide study. *Res Autism Spectr Disord*. 2015;10(201):1-6. doi:10.1016/j.rasd.2014.10.014
35. Roux AM, Garfield T, Shattuck PT. Employment policy and autism: Analysis of state Workforce Innovation and Opportunity Act (WIOA) implementation plans. *J Vocat Rehabil*. 2019;51(3):285-298. doi:10.3233/JVR-191046
36. van Asselt-Goverts AE, Embregts PJCM, Hendriks AHC, Wegman KM, Teunisse JP. Do Social Networks Differ? Comparison of the Social Networks of People with Intellectual Disabilities, People with Autism Spectrum Disorders and Other People Living in the Community. *J Autism Dev Disord*. 2015;45(5):1191-1203. doi:10.1007/s10803-014-2279-3
37. Orsmond GI, Shattuck PT, Cooper BP, Sterzing PR, Anderson KA. Social participation among young adults with an autism spectrum disorder. *J Autism Dev Disord*. 2013;43(11):2710-2719. doi:10.1007/s10803-013-1833-8
38. Jaswal VK, Akhtar N. Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*. 2019;42. doi:10.1017/S0140525X18001826
39. Nicolaidis C, Raymaker D, McDonald K, et al. Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. *J Gen Intern Med*. 2013;28(6):761-769. doi:10.1007/s11606-012-2262-7
40. Leung RC, Vogan VM, Powell TL, Anagnostou E, Taylor MJ. The role of executive functions in social impairment in Autism Spectrum Disorder. *Child Neuropsychology*. 2016;22(3):336-344. doi:10.1080/09297049.2015.1005066

41. Mason D, Ingham B, Urbanowicz A, et al. A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *J Autism Dev Disord*. 2019;49(8):3387-3400. doi:10.1007/s10803-019-04049-2
42. Crane L, Adams F, Harper G, Welch J, Pellicano E. 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism*. 2019;23(2):477-493. doi:10.1177/1362361318757048
43. Rumball F, Happé F, Grey N. Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events. *Autism Research*. Published online 2020:1-11. doi:10.1002/aur.2306
44. Rumball F. *A Systematic Review of the Assessment and Treatment of Posttraumatic Stress Disorder in Individuals with Autism Spectrum Disorders.*; 2018. doi:10.1007/s40489-018-0133-9

Table 1: Demographic characteristics of the sample.

		Full sample (n=79)	
Age, years	<i>M (SD) [Range]</i>	45.52 (12.18) [21 – 75]	
Gender	<i>Female</i>	47	(58.0%)
	<i>Male</i>	26	(35.0%)
	<i>Non-binary</i>	6	(7.0%)
Living arrangement*	<i>With partner/spouse</i>	40	(50.6%)
	<i>With children</i>	18	(22.8%)
	<i>With a sibling</i>	2	(2.5%)
	<i>With a parent</i>	14	(17.7%)
	<i>With other family</i>	3	(3.8%)
	<i>With a roommate</i>	4	(5.1%)
	<i>Living alone</i>	17	(21.5%)
Education History	<i>School to 16</i>	5	(6.3%)
	<i>School to 18</i>	19	(24.1%)
	<i>Undergraduate</i>	27	(34.2%)
	<i>Postgraduate</i>	28	(35.4%)
Employment status	<i>Employed</i>	45	(57.0%)
	<i>Retired</i>	6	(7.6%)
	<i>Unemployed</i>	6	(7.6%)
	<i>Unable to work due to health</i>	22	(27.8%)
Autism diagnosis status	<i>Diagnosed</i>	68	(86.1%)
	<i>Self-Identified</i>	11	(13.9%)

*Note. *Participants were asked to select all living arrangement options that applied to them, thus the total ≠ 100%.*

Table 2: Selection of illustrative quotes from Theme 1: The impact of the first COVID-19 pandemic lockdown on health.

Subtheme	Quote
1A: The widespread impact of mental health	<ul style="list-style-type: none"> - <i>“Despite the distressing experience of changing all of my routines, I wish [social distancing, working from home] would last forever... I’m sick and worried about returning to my previous lifestyle after lockdown” [Autistic woman, mid-50s, ID#53].</i> - <i>“At the beginning of lockdown overall wellbeing got better - no outside pressures. Since lockdown eased it has got worse because of unclear information and fear of using public transport and facilities again.” [Autistic woman, early 60s, ID#27].</i> - <i>“I have found my depression worsen over the pandemic and I’m feeling hopeless every day.” [Autistic woman, late-40s, ID#83].</i> - <i>“My anxiety started to go up during lockdown which meant I started to feel very low.” [Autistic woman, early 20s, ID#32].</i>
1B: A growing sense of anxiety	<ul style="list-style-type: none"> - <i>“I feel the general anxiety in the population is ‘catching’.” [Autistic man, early 60s, ID#26].</i> - <i>“I worry about the changes to my working routines and patterns, along with returning back to the office.” [Autistic man, late-50s, ID#22].</i>
1C: Worrying about the impact of restrictions	<ul style="list-style-type: none"> - <i>“I have been unable to use distraction techniques that I would have used to raise my mood when it begins to dip, so my mental health has become worse.” [Autistic woman, early 60s, ID#76].</i> - <i>“I am prone to worry and catastrophizing, so I normally rely on occasional activities to get out of my head. It is harder to do things now with the lockdown.” [Autistic woman, late-30s, ID#49].</i>
1D: Difficulties with camouflaging their mental health	<ul style="list-style-type: none"> - <i>“I’m worried about my depression seeping through in inappropriate ways when I speak to people. I feel like my social interaction skills are worse because my mental health is worse. It’s hard to hide how I feel.” [Autistic woman, early 30s, ID#47].</i> - <i>“I’ve become quite isolated. My physical and mental health also play a big factor in worsening my social skills.” [Autistic person, mid-50s, ID#20].</i>
1E: Lifestyle changes leading to changes in physical health and general fitness	<ul style="list-style-type: none"> - <i>“I was able to lose some weight and I’ve been doing a lot more exercise. I feel great” [Autistic woman, late-40s, ID#10].</i> - <i>“I’ve made a lot of dietary and exercise routine changes which have led to an improved physical appearance and ability.” [Autistic man, late-20s, ID#87].</i> - <i>“I’ve been able to do a bit more exercise, eat better food, and I’m less stressed from not commuting.” [Autistic woman, late-20s, ID#62].</i> - <i>“I’ve tried to continue with my physical exercise in lockdown but I’m finding it hard to motivate myself. It just feels pointless.” [Autistic woman, early 50s, ID#41].</i> - <i>“I have been overeating through anxiety/boredom and not taking my usual amount of exercise which has impacted my general health.” [Autistic woman, early 60s, ID#75].</i>

Table 3: Selection of illustrative quotes from Theme 2: Social Changes and Theme 3: Changes to formal and informal support provisions

Subtheme	Quote
2A: Less pressure to socialise	<ul style="list-style-type: none"> - "Nobody is making me feel like I should be more sociable" [Autistic woman, late 60s, ID#22]. - "In some ways, lockdown was nice as I didn't have to feel guilty or make excuses for not wanting to socialise outside of work" [Autistic woman, mid-30s, ID#71] - "I don't really experience loneliness. I enjoy being alone all the time as it's the best thing for me" [Autistic person, mid-30s, ID#94]. - "The distancing is a dream situation for me" [Autistic woman, mid-50s, ID#53]. - "The lockdown has simplified my life, given it a slower pace, made it calmer, given me more time to keep on top of things, and reduced my socialising to a level I can cope better with." [Autistic woman, early 50s, ID#13].
2B: Experiences of social isolation and loneliness	<ul style="list-style-type: none"> - "The isolation comes from not being able to access grocery stores and services" [Autistic woman, early 60s, ID#75]. - "Shielding has been very difficult. It's increased my loneliness and I feel very isolated." [Autistic woman, late 50s, ID#33]. - "Although I am a complete introvert, being isolated so much has been very unhealthy for me, and I find it hard to leave the house at all now." [Autistic man, early 60s, ID#29]. - "I like being on my own and having space, but I feel isolated sometimes in a crowd." [Autistic woman, late 40s, ID#7].
2C: Using digital communication tools to remain socially integrated	<ul style="list-style-type: none"> - "I find using online meetings less stressful. I feel less anxiety in video calls with my co-workers compared to in-person meetings. I also think the camouflaging needs are much simpler" [Autistic woman, mid-50s, ID#18]. - "It has forced the wider world to adopt methods of communication which are better suited to my needs, such as online meetings rather than in person. I hope online meetings will continue". [Autistic woman, late 30s, ID#60]. - "I'm having to learn how to communicate virtually now. I long for a time when I can meet my friends physically again." [Autistic woman, mid-50s, ID#54].
2D: Becoming out of practice	<ul style="list-style-type: none"> - "I feel like my social skills have got worse. I hate online meetings. I am always very anxious about how I am perceived and things like blurting things out by mistake when it's not my turn to speak" [Autistic woman, early 30s, ID#47]. - "I go out less so I practice less. When I do go out, I find interacting with people difficult and I am much more silent in public than I used to be." [Autistic man, early 60s, ID#78].
3A: Dealing with changes to service and new policies	<ul style="list-style-type: none"> - "I'm worried about my sleep clinic appointment being cancelled since there was already such a long wait to get it." [Autistic woman, early 50s, ID#53]. - "The whole process of trying to see a doctor has become far more complicated and requires jumping through many hoops." [Autistic man, early 60s, ID#46]. - "The replacement services concentrated on employment only which is not the support I need." [Autistic man, early 60s, ID#93]. - "I was given the option of continuing my counselling support by phone or to be discharged. I didn't feel able to do it by phone, so I had no choice but to be discharged. I really want some help with my mental health, but I just don't know where to turn. Even the autism service is phone only at the moment" [Autistic woman, mid-50s, ID#16]. - "I was seeing a counsellor but felt I couldn't continue with it online" [Autistic woman, mid-50s, ID#13]. - "I can only praise my GP and CBT therapists for keeping in contact by phone and offering video appointments. I have asked if video appointments could be kept as a regular option to see them as they were better for me." [Autistic woman, mid-50s, ID#53].
3B: Opting to cancel appointments	<ul style="list-style-type: none"> - "I'm nervous about going in [to hospital]. Wearing a face mask helps against the virus but isn't perfect. I think a lot of people, autistic too, are feeling this" [Autistic woman, mid-50s, ID#18]. - "I can't speak to my GP in their face mask. I feel uncomfortable going in, so I won't go" [Autistic woman, early 60s, ID#25].
3C: Reaching out to family and friends	<ul style="list-style-type: none"> - "It feels like the world has shut down. The new rules and policies that have been put in place mean that my formal support has disappeared. But I have my family around me and take comfort in us all being in this together." [Autistic woman, early 50s, ID#05]. - "I am very bad at asking for help outside a clinical structured setting like therapy." [Autistic woman, mid-50s, ID#18]. - "My partner and I are currently going through a rough patch, directly related to issues caused by the current situation. I can no longer confide in them; I have children but would not involve them in my issues at all." [Autistic man, early 60s, ID#93]. - "I've become too dependent on wife since the lockdowns have started, and unfair on her." [Autistic man, late 50s, ID#12].

Table 4: Selection of illustrative quotes from Theme 4: Adopting new routines and adapting to new environments

Subtheme	Quote
4A: Change in routine altering sleep patterns and behaviours	<ul style="list-style-type: none"> - <i>"I've always struggled to sleep at night unless I am incredibly fatigued. It is even harder now as I no longer have to leave for the office. Staying up late has become the norm and I no longer bother to wake up in the morning" [Autistic man, late 20s, ID#86].</i> - <i>"Because my timetable of getting up at 5:30 has now stopped, it has been difficult to change the sleeping pattern and I just feel tired all the time." [Autistic woman, mid-40s, ID#57].</i> - <i>"I have full on dreams every night which take so much out of me and I don't understand why they're happening." [Autistic woman, early 20s, ID#39].</i> - <i>"I usually wake up in the middle of the night and worry about everything. My mind is a jumble of thoughts and images. I am usually awake from 3am until it is time to get up, and that is sometimes as early as 5:30am." [Autistic man, early 60s, ID#93].</i>
4B: Disruptions leading to problems with cognitive function	<ul style="list-style-type: none"> - <i>"I thought that having a slower pace of life would help my poor executive functioning, but it hasn't" [Autistic woman, early 50s, ID#13].</i> - <i>"My memory and concentration are worse. Sleep problems and stress make me less able to function. It is harder for me to mask my autism and appear level-headed and competent as I am constantly worried and distracted" [Autistic woman, mid-30s, ID#71].</i> - <i>"My memory is getting bad. I'm starting to forget silly little things and I struggle to concentrate on tasks." [Autistic woman, early 50s, ID#41].</i> - <i>"I now have a poor sense of time because everything is out of normal routine. I've started mixing up bus times and directions to bus stops." [Autistic woman, mid-50s, ID#53].</i> - <i>"I have difficulty concentrating on my studies as I have been constantly distracted and upset by bad news from around the world" [Autistic woman, late 50s, ID#23].</i> - <i>"Because of pressure and mental health issues, I find it difficult to concentrate on tasks for more than about five minutes at a time. I often find myself distracted and unable to pick what to do at any time". [Autistic man, early 60s, ID#93].</i>
4C: Time to reflect and the importance of self-care	<ul style="list-style-type: none"> - <i>"Lockdown has allowed me time/headspace to process more." [Autistic woman, late-30s, ID#60].</i> - <i>"I've been focusing heavily on self-care during the pandemic. My mental health has seen a big slip recently which has opened up old traumas, but it is slowly getting better." [Autistic man, late-20s, ID#87].</i> - <i>"I've also come to really appreciate the importance of self-care and hobbies which for me include, singing, painting, and creative writing, and dancing." [Autistic woman, early 20s, ID#39].</i> - <i>"I find it difficult remembering to have a shower and tidy up" [Autistic person, mid-30s, ID#94].</i>
4D: Controlling sensory environments	<ul style="list-style-type: none"> - <i>"I am able to tolerate others better now because of the reduced exposure to the outside stimulus. I still prefer going out at night as it is quieter though." [Autistic woman, mid-50s, ID#53].</i> - <i>"It's good that rules are clear in shops. I find it helpful as I like to know what is expected and that I am behaving appropriately. I like the personal space that comes with social distancing" [Autistic woman, early 30s, ID#80].</i>
4E: Concerns about adjusting back to previous sensory environments	<ul style="list-style-type: none"> - <i>"Because I have not had the ability to consistently confront sensory issues to de-sensitise, when I did attempt a trip to the garden centre, which I would usually have been able to accommodate, I suffered a severe panic attack and sensory overload" [Autistic woman, early 60s, ID#75].</i> - <i>"It's gone from quiet, silent and empty during the lockdown, to crowded, noisy and chaotic again. It's completely overwhelming" [Autistic woman, early 60s, ID#25].</i> - <i>"I feel I am even more sensitive to noise now than I was before lockdown" [Autistic man, late 30s, ID#52].</i> - <i>"I am more often indoors so I am less likely to be exposed to loud noises, bright lights, but then I am less used to them so they have a greater impact when I do encounter them" [Autistic man, early 30s, ID#34].</i>