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COVID-19, social isolation and the mental health of autistic people and their families: a qualitative study

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Abstract

The COVID-19 pandemic and its policy responses have had a detrimental effect on millions of people's mental health. Here, we investigate its impact on autistic people and their families using qualitative methods. Specifically, we addressed: How did autistic people experience the increase in social isolation during the initial lockdown? And how was their mental health impacted by lockdown? Autistic and non-autistic researchers conducted 144 semi-structured interviews with autistic adults (n=44), parents of autistic children (n=84) including autistic parents, and autistic young people (n=16). We deployed thematic analysis to identify key themes. The enhanced social isolation accompanying the pandemic had a serious and damaging impact on autistic people's mental health and subjective wellbeing. They spoke of intensely missing friends and more incidental forms of social connection. They also reported intense dissatisfaction with the substitution of embodied, person-to-person connection in health services by online/telephone-based alternatives, sometimes accompanied by serious negative consequences. These findings reveal the fundamental importance of supporting autistic people to maintain direct and incidental social contact during the pandemic and beyond. They speak against established theories that downplay autistic people's need for human connection and the extent to which they have been affected by social isolation during lockdowns.

Introduction

COVID-19 and the restrictions that have followed in its wake are widely perceived to have undermined the mental health of millions of people worldwide, with potentially vulnerable groups faring worse than the overall population (Banks & Xu, 2020; Cresswell et al., 2021; Czeisler et al., 2021; Holmes et al., 2020; O'Connor et al., 2020). There are good reasons to believe that autistic people and their families have been particularly disadvantaged (Pellicano & Stears, 2020): prior to 2020, autistic[1] people and their families were more likely than the general population to experience socio-economic exclusion (e.g., Churchard et al., 2019; Howlin & Magiati, 2017), to be diagnosed with psychiatric conditions, especially anxiety and depression (Lai et al., 2019), and to experience medical conditions, including those affecting the immune system (Croen et al., 2015). Autistic people are also often uncomfortable with swift, unexpected change (American Psychiatric Association [APA], 2013), can struggle to deal with uncertainty (Jenkinson, Milne, & Thompson, 2020), and can be heavily reliant on health, social care and related services that have proven hard to maintain during the pandemic.

Despite all of this, prominent theoretical accounts of autism give us reason to expect that autistic people might have responded more positively than others to the restrictions on social interactions during COVID-19. Such theories imply that autistic people's sociocognitive differences entail that they do not engage in social interaction in the same way that neurotypical people do (Baron-Cohen, 1995; see Happé, 2015, for review), and some scholars have gone further to suggest that these sociocognitive differences are a result of significantly diminished social motivation (APA, 2013; Chevallier, Kohls, Troiani, Brodkin, & Schultz, 2012; Dawson et al., 2005; Mundy, 1995; see Jaswal & Akhtar, 2019, for critique). Indeed, Chevallier et al. (2012) have "defend[ed] the idea that social motivation is a powerful force guiding human behaviour

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[1] In the autistic community, identity-first language, e.g., "autistic person", is often preferred to, and considered less stigmatizing than, person-first language, e.g., "person with autism" (Gernsbacher, 2017; Kenny et al., 2016). It is also the terminology preferred by our autistic co-researchers. We therefore use identity-first language throughout, unless participants themselves have used person-first language, which we retain in their quotes.

and that disruption of social motivational mechanisms may constitute a primary deficit in autism" (p. 231).

Given this purported reduced motivation for social connection in autistic people, it is reasonable to expect that these theoretical accounts would predict that at least some autistic people may have welcomed the isolation brought about by government action to halt the spread of infection, or at least not to have suffered directly as a result of their reduced social interactions. If so, they may have fared better than expected during this period. The actual theoretical accounts, of course, make no explicit predictions about the impact of pandemic public policy, published as they were long before COVID-19, but Chevallier et al. (2012) did suggest that the "adverse effects of social isolation on well-being are a natural consequence of the strength of social motivation" (p. 233). It is unsurprising, therefore, that, partly as a consequence of these theoretical accounts, autistic people have since been described as "natural quarantiners" (Cassidy et al., 2020, p. 110). Accounts in the mainstream media and in popular clinical commentary have even deployed these theoretical accounts to suggest autistic people's approach to "social isolation" provides "a unique perspective" from which non-autistic people could learn as they try to "cope" with the pressures of the pandemic (Ransdell, 2021).

Emerging research on the psychological impact of COVID-related restrictions on autistic children (Asbury et al., 2020; Oakley et al., 2020) and adults (Adams et al., 2021; Bal et al., 2021; Oomen, Nijhof, & Wiersem, 2020) is so far inconclusive on the question of how autistic people fared given the restrictions on social interaction during the pandemic. In line with the above perspective, some emerging research has revealed positive effects of the COVID-related lockdowns for autistic children, young people and adults, and their families. For example, Mumbardó-Adam et al. (2021) found that parents of autistic children in Spain reported that their children "managed quarantine better than expected", and that during COVID-19 restrictions, their children were more communicative and more likely to participate in family life than pre-pandemic. Other studies have also reported that the removal of many everyday pressures have resulted in some autistic children (Asbury et al., 2020; Rogers et al., 2021) and adults (Oomen et al., 2021) feeling more relaxed during the COVID-19 lockdowns. Others suggest that, despite being subject to high levels of stress and anxiety prior to the pandemic, autistic young people and adults weathered pandemic restrictions effectively, with no changes in measures of mental health and stress among autistic young people (Corbett et al., 2021) and adults (Adams et al., 2021; Bal et al., 2021) during the restrictions.

Contrasting research, however, provides initial reasons to doubt this positive view. In Asbury et al.'s (2021) survey of 241 parents of school-aged children with special educational needs and disabilities in the United Kingdom (UK), most of whom were autistic, the majority reported experiencing increased anxiety and low mood. Amorim et al. (2021) similarly showed that Portuguese parents of autistic children reported sometimes intense anxiety during lockdown, both for themselves and their child, compared to caregivers of non-autistic children. Other studies, focusing on the psychological consequences of the COVID-19 pandemic on autistic adults specifically, demonstrated that between 45% (Bal et al., 2021) and 66% (Adams et al., 2021) of their US-based samples reported psychological distress early in the pandemic, which appeared to be exacerbated in those with elevated levels of anxiety prior to the pandemic. Oomen et al.'s (2020) study critically revealed another key source of mental health distress in autistic adults from Belgium, the Netherlands and the UK (n=613): while their participants reported feeling relieved from everyday social stresses, they experienced the loss of social contact as particularly difficult.

Most of these studies, though, are limited by the minimal involvement of autistic people in the research process (see Holmes et al., 2020; Moreno et al., 2020) and their reliance on survey methodology, which, even with open-ended questions, can fail to capture the complexity of people's day-to-day experiences, potentially obscuring subtle experiences and reflections.

Here, therefore, a research team composed of both autistic and non-autistic researchers deployed in-depth qualitative interviews in order to access the subjective, everyday experiences of autistic people during the pandemic. Specifically, we sought to establish how autistic people experienced, and responded to, the increase in social isolation during governments' stay-at-home orders, and whether it eased or intensified long-standing challenges to their mental health.

Method

Participants

Participants from three groups – autistic adults, autistic young people aged 12-18 years, and parents of autistic children – were recruited. On the 6th May 2020, we advertised the study on social media inviting people to participate in an interview-based study (see Supplementary Figure 1). We received 150 expressions of interest within 48 hours; study enrolment therefore closed. To be eligible, participants needed to be English speaking, and willing and able to convey in-depth personal experiences of the pandemic. Parents were also required to have a child, of any age, who had received a clinical diagnosis of autism, according to DSM-IV-TR or DSM-5 criteria (APA, 2000; APA, 2013). Adults were included if they either had received a clinical diagnosis of autism or self-identified as autistic, to account for the often-significant delays for some in gaining a clinical diagnosis (Lai & Baron-Cohen, 2015).

We interviewed all eligible participants (n=144) between 19th May and 29th June 2020. Participants ranged in age from 12 to 69 years and included 44 autistic adults, 84 parents of autistic children, 35 of whom were autistic themselves, and 16 autistic young people (Table 1). The majority of participants came from Australia (n=130; 90%). Adult participants (n=128) reported themselves to be predominantly of white ethnic background (n=110; 86%) and moderate-to-high socioeconomic status. Of the 144 participants, 106 (74%) reported staying at home and following government physical distancing rules, while the remaining 38 (26%) were self-isolating either due to suspected COVID-19 (n=4; 3%), formal health vulnerability (n=20; 14%), or other related reasons, e.g., pre-existing condition (n=8; 6%). Only six participants (4%) were interviewed after initial restrictions had eased significantly.

Autistic adults. Forty-four autistic adults participated, ranging in age from 23 to 69 years (see Table 1). Twenty-eight were women, 12 were men, three were non-binary and one reported their gender as "other". Of the 44 adults, 41 had received independent clinical diagnoses of an autism spectrum condition between the ages of 2 and 64 years (M=31.46; SD=13.89) from either a general practitioner (n=1), psychiatrist (n=7), clinical psychologist (n=22), speech therapist (n=1) or a team of health professionals (n=10); the remaining three self-identified as autistic. Seventeen autistic adult participants (39%) had received diagnoses of other neurodevelopmental conditions. Most reported having received often multiple diagnoses, especially co-occurring diagnoses of anxiety *and* depression (n=19; 43%) (see Table 1). Prior to the COVID-19 pandemic, the majority (n=28; 64%) were in some form of employment (see Table 1 main paper). Almost one quarter of our sample (n=10, 23%) had experienced a change in their occupational status during the COVID-19 outbreak.

[insert Table 1 about here]

Autistic young people. We spoke to 16 autistic young people, aged between 12 and 18 years, including five girls, eight boys, two with non-binary gender and one who was gender-questioning (see Table 2). All young people had received an independent clinical diagnosis of Asperger's syndrome (n=5), autism (n=2) or autism spectrum disorder (n=9), according to either DSM-IV-TR (APA, 2000) or DSM-5 (APA, 2013) criteria. They had received their diagnosis, on average, at the age of 8 years 4 months (SD: 3.8; Range = 2 – 16 years). Of the 16 young people who took part, 12 reported co-occurring diagnoses of often-multiple neurodevelopmental and/or psychiatric conditions. Most notably, almost two thirds (n=10; 62.5%) had a pre-existing diagnosis of anxiety and/or depression (see Table 1 main paper). All young people were living with their families during the study period, with the exception of one young person who had been admitted to a long-stay hospital facility during the COVID-19 pandemic due to mental health issues.

Parents of autistic children. Eighty-four parents of autistic children were interviewed. Forty-nine parents (58%) reported that they did not have an autism diagnosis themselves, while the remaining 35 (42%) reported either having received an independent clinical diagnosis of an autism spectrum condition (n=26; at an average age of 42.92 years, SD=6.63) or self-identified as autistic (n=9). The latter two groups were therefore combined into an 'autistic parent' group. Table 1 shows background characteristics for the two groups. Parents reported themselves to be predominantly of white ethnic background and moderate-to-high socioeconomic status.

Together, the 84 parents reported on their 116 autistic children (M age=10.7 years, SD=4.8; range = 3–29), most of whom (n=103; 88%) were of school age and enrolled largely in mainstream school settings (n=103; 87%; Table 2). Of the 61 children (52%) in the non-autistic parent group, 13 (21%) were girls/women, 47 were boys/men (77%) and one was non-binary (2%). Their children ranged in age from 3.30 – 29.11 years (M=11.07; SD=5.66). Of the 55 children (48%) in the autistic parent group, 22 were girls/women (40%), 30 were boys/men (54%) and 3 were non-binary (5%). Their children ranged in age from 3.98 – 25.33 years (M=10.21; SD=4.04). Most children (n=92; 79%) across the two groups were reported to have additional co-occurring psychiatric or medical conditions (see Table 2), most commonly ADHD and anxiety disorder.

[insert Table 2 about here]

Procedure

All procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. Ethical approval for this study was granted by the Human Research Ethics Committee at Macquarie University (Project ID 6665). All participants, including young people, provided written informed consent prior to taking part; parents provided additional consent for young people. We followed the Standards for Reporting Qualitative Research guidelines (O'Brien et al., 2014).

Prior to the interview, participants provided information about their age, gender, ethnic/racial background, autism and/or other co-occurring diagnoses, educational, occupational status and other background details, including COVID-related information and isolation status, via an online questionnaire (~10-15 minutes) powered by LimeSurvey. Parents provided background information about their children, and about their own clinical/self-diagnosis of autism, if applicable.

Participants then completed individual semi-structured interviews via their preferred means of communication, including video-conferencing (Zoom), telephone, email, or live text-based chat. Young people had the option of being interviewed alongside their parents or another support person. We asked each participant a series of open-ended questions about their day-to-day experiences of the pandemic and its perceived impact on their living, working and learning arrangements, social relationships, access to services and sense of wellbeing. The questions were reworded to suit their different roles. Primary interview questions were provided to participants ahead of the interview to accommodate processing differences.

Interviews were predominantly conducted over Zoom (n=103; phone: n=21; email: n=18; live text-chat: n=2) and varied in length, between 15.20 and 99.44 mins (M=50.40, SD=20.40; Table 1). People spoke to us, on average, for 55 minutes (range = 15 – 100 mins). Participants received an AUD $25 (or equivalent) voucher as a thank you for their time. All Zoom or telephone interviews were recorded with participants' prior permission and transcribed verbatim by a transcription service. Transcripts were then returned to each participant for review, to ensure accuracy and to remove any details, should they wish.

Data analysis

Our analysis was informed by team members' experience and training in psychology or psychiatry (EP, JDH, IM and SB), allied health (AU) and public policy (MS), and by their relevant positionalities as autistic researchers (JDH, MH, RS). We followed Braun and Clarke's (2006, 2019) method for reflexive thematic analysis within an essentialist framework, in which our goal was to report the meanings and experienced reality of the participants. In so doing, we deployed an inductive approach (i.e., without integrating the themes within any pre-existing coding schemes or preconceptions of the researchers) to identify patterned meanings within the dataset. The analytic process began during data collection, where the team met regularly to discuss patterns in the data, including potential codes and analytic 'noticings'. Once all interviews had been transcribed, one senior researcher (EP) immersed themselves in the data, reading all transcripts twice, taking reflexive notes on striking and recurring observations and applying codes to each transcript (managed in NVivo, version 12). Data were initially coded separately by group (autistic young people, autistic adults, parents). It soon became apparent through discussion that the codes and potential themes were common across informants. The same codes were therefore applied to all transcripts and the initial transcripts were re-coded, where necessary. Codes were clustered together to identify candidate themes and subthemes. EP then generated a draft thematic map, and the relevant data were collated under each theme and subtheme. The draft analysis was reviewed and revised initially by MS and RS and then discussed and reviewed multiple times with the broader team, focusing on semantic features of the data (staying close to participants' language). The themes were also discussed with participants (n=5), including one young person[2]. Analysis was therefore iterative and reflexive (Braun & Clarke, 2019).

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[2] All participants were sent an initial report of the findings and invited to comment. Five participants provided in-depth comments and these participants were contacted again about the specific themes for this paper. We did not further follow-up those who did not respond to our initial invitation to comment. Taking part in our study was already onerous for our participants – involving in-depth interviews in issues of some potential emotional difficulty – and we did not believe it was ethical to require or expect participants to engage still further in the work unless they expressed the wish to do so.

Community Involvement

A team of autistic and non-autistic researchers worked together to elicit the experiences of autistic people and families during the COVID-19 pandemic. The lead author conceived of the study, drew on existing funding to support it, and drew on established collaborative relationships to design and implement it, analyse the results and disseminate the findings. The lead author had worked previously with each of the autistic team members on prior projects, investing considerable time in ensuring that influence was shared within the team and that autistic experience was prioritised in research design and analysis.

All collaborators actively contributed from the outset of the project, resulting in collaborative decisions in regard to methodology, including eligibility criteria, sampling characteristics, the nature and content of each interview, and the procedure itself, including drafting the ethics application. All autistic authors conducted interviews with participants and were supported in doing so, interviewing at least 10 participants each. The allocation process was also done in such a way to ensure, where possible, that autistic collaborators were allocated interviewees whose desired interview format (e.g., email/live-text chat) aligned with their own communication preferences. Autistic authors were also involved in analysing and interpreting the data and disseminating the results. Team members were encouraged to communicate their views at every stage of the process during Zoom meetings, via email and on the various documents.

The collaboration between autistic and non-autistic researchers ensured that the methods were thorough, respectful and supportive of our participants' needs and wishes, including that all study information documents were accessible (through the use of Plain English text and images to accompany the text); participants could choose among several formats for their interviews; and the language and presentation of all correspondence aligned with the values of the autistic community. Working together in this way also means that recruitment targets were reached exceptionally quickly (see Participants section), and the results were interpreted through a strengths-based, rather than deficits-based, lens.

Results

Following analysis, we identified three themes that addressed our research questions. Participants felt (1) a release from the demands of conventional social challenges; combined with (2) a deep sense of social loss; and (3) a deterioration of mental health. Figure 1 shows the themes and associated subthemes, which are also numbered below and presented in bold and italics, respectively. Illustrative quotes are also provided below and in Supplementary Table 2, attributed via participant IDs to demonstrate that the themes reflect a range of participants' perspectives (YP: Young person; AUT: Autistic adult; AUTParent: Autistic parent; NAParent: Non-autistic parent).

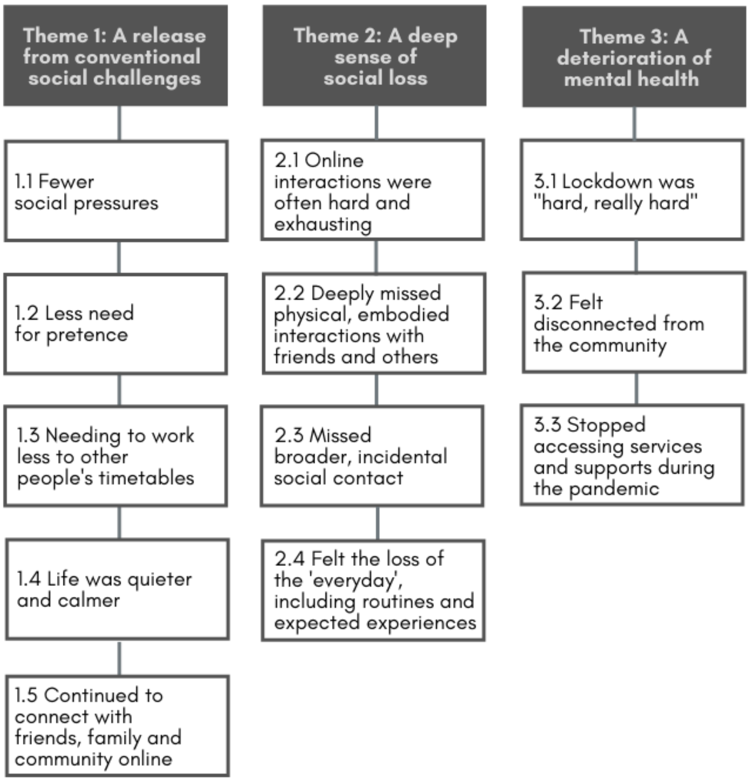

Figure 1. Participants' perspectives on the COVID-19 pandemic: themes and sub-themes.

Theme One: A release from conventional social challenges. For our participants, the early COVID-19 restrictions were often described as "freeing" [012-AUT]: "[they] ironically allowed me to breathe for the first time in years" [210-AUTParent]. There were several aspects of being released from social interaction that they enjoyed.

One key aspect was the *fewer social pressures* (subtheme 1.1). People spoke of being released from some of the normal "obligations to be social" [203-AUTParent] and the difficulties "taking on the burden of the expectations of others" [016-AUT] that dominated their lives prior to COVID-19. The absence of these social demands meant that there was *less need for pretence* (subtheme 1.2). The lockdown meant they could "just be ourselves" [211-AUTParent]. There was also "relief" in *needing to work less to other people's timetables* (subtheme 1.3). Young people reported enjoying being able to "wake up late" [113-YP] and to have "five, ten minutes to sit back and stretch and relax" [105-YP] in-between lessons. This meant that "now we have time. We can slow down, focus more on us than stuff we have to get done" [109-YP]. These more flexible schedules also meant that they could pursue their passions – which ranged from reading, chess, sewing, playing Animal Crossing, Minecraft or World of Warcraft, baking, choir, singing, painting, sculpting, gardening, building Lego, to renovating the house. Some attended online groups that were "the highlight of my week" [204-AUTParent].

Consequently, participants described *life as quieter and calmer* (subtheme 1.4). Young people reported that remote learning "is a lot better actually than regular school [due to the] peace and quiet" [105-YP]: "it just fits my needs better … I don't have to be in a loud place with loud people" [102-YP]. Participants also described enjoying being able to *connect with friends, family and community online* (subtheme 1.5) "on Zoom, Skype, Facetime and whatever else you can think of" [040-AUT]. In the early days of the pandemic, these connections extended to the broader community, including having "more connection with the neighbours than usual" [039-AUT], and online autistic groups: "I don't know where I'd be without the autistic community … there's that common understanding as to how people feel" [005-AUT].

Theme Two: A deep sense of social loss. Despite these gains, participants felt the benefits of lockdown were often overshadowed by an overwhelming sense of loss, especially loss of valuable social experiences. Although they were able to connect with friends, family and community, as time wore on *online interactions were often hard and exhausting* (subtheme 2.1). People struggled with Zoom: "you lose even more sense of body language and intonation and all that kind of stuff" [013-AUT]. One adult described how this extended to the new home-working arrangements: "just the constant stream of trying to interpret and process and understand the language in the emails" [010-AUT]. Parents also reported that their children "really struggled with the video call side of things" [217-AUTParent] and "did not tolerate Zoom" [324-NAParent], feeling that technology was "a poor substitute for real interaction" [218-AUTParent].

Strikingly, our participants reported *deeply missing physical, embodied interactions with friends and others* (subtheme 2.2). This sentiment was overwhelmingly common among young autistic participants, who described how "they prefer hanging out … in person" [205-YP]. Adults agreed that online interactions were not enough – "we're more than pixels on a screen" [043-AUT] – and parents also described that their children "felt very disconnected … he missed being in their presence and really needed that face-to-face, in-person connection" [211-AUTParent]. Some participants expressed surprise at how much they missed their friends, especially those interactions "we have control over" [005-AUT]. Parents also reported how much of "an eye-opener it was for us, particularly around the socialising and how much [child] missed people" [332-NAParent]. This was the case even for children with limited spoken communication (Supplementary Table 2).

For some participants, the desire for social contact went further, meaning they also *missed broader, incidental social contact* (subtheme 2.3). One autistic adult explained, "just interacting and talking about little things … someone to keep the time of day, how they went and all those sorts of personal conversations have gone for me. I'm not getting any of that at all" [020-AUT]. Another autistic parent described a growing appreciation for "people and social contact more than we used to … people passing each other on the streets are smiling and greeting each other more, I tolerate idle small talk with random people a lot more" [223-AUTParent]. Again, participants expressed surprise at "how much I actually need human interaction and how much humans actually are somewhat a valuable component of my life" [007-AUT].

Our participants also deeply *felt the loss of their everyday routines and expected experiences* (subtheme 2.4). Young people felt worried that "I don't get to see my friends or my family that much, and I don't get to go to the places I usually go – the library and places like that" [110-YP]. Adults reported missing the rhythm of their usual routines of "netball games on Sunday nights" [004-AUT], "sports training as a group" [003-AUT], and "ballroom dance class … which is one of my big social outings for the week" [011-AUT]. Participants were unable to engage in the kinds of everyday activities that many had strived hard to access in the past and which were essential for wellbeing. For some, even "the meaningless stuff had become … meaningful and needed" [234-AUTParent].

Theme Three: A deterioration of mental health. Participants perceived this loss as impacting directly on their mental health. One autistic parent reported that "my self-care routine was shot to pieces" [229-AUTParent]. Lockdown was described as "this dead air, this empty space that in some ways was less stress but in other ways it was more stress … and I wasn't energised, and I just had no purpose" [228-AUTParent]. Overwhelmingly, participants felt that *lockdown was "hard, really hard"* [326-NAParent] (subtheme 3.1).

These sentiments were manifested in each participant group. Young people described feeling "a lot more flat" [105-YP], "really stressed and having intrusive thoughts" [114-YP], and how "my thoughts are almost not really my own anymore" [101-YP]. One reported, "when COVID started, I made a chart, and the chart is to map out how many times I've felt just so sad that I just wanted to die. Just die" [103-YP]. Autistic adults also spoke of "significant mental health impacts" [009-AUT]. They reported "all the physical symptoms of anxiety, nausea, vomiting, shaking, you know, hyperventilating from time to time" [008-AUT]. Some "felt incredibly vulnerable" [042-AUT] and "lonely, just lonely" [007-AUT], "unable to see anything positive into the future" [019-AUT]. For some, the impact was so severe that they "hit breaking point" [023-AUT], ending up in emergency psychiatric care. One participant's account was particularly distressing:

> I really struggled with this crisis. I am a young autistic man with daily challenges to face, but this one was really hard … for the third time, I tried to commit suicide. This time was the worst. I stayed in a coma for two days and I woke up in intensive care, intubated [037-AUT]

Parents reported similar effects in their children, who were "really distressed" [310-NAParent]; "shut down a lot more" [340-NAParent]; "in tears and sobbing" [202-AUTParent]; "had outbursts of crying, like inconsolable crying" [319-NAParent]; had nightmares ("every night he woke up screaming" [343-NAParent]) and "daily multiple panic attacks" [219-AUTParent]; or had become "more aggressive and physically violent" [333-NAParent]. Some children had begun to self-harm and were "suicidal" [313-NAParent]. One parent summed up her child's experience: "his words were, 'I hate COVID, it's turned my world upside down'" [202-AUTParent].

Parents also stressed how difficult it was "just being in survival mode" [227-AUTParent]. They described that "it's been hard to have that energy to be like a teacher now and a parent 24 hours a day, and also a therapist" [304-NAParent] and that their "mental health has deteriorated" as a result [328-NAParent]. This appeared to be exacerbated in the case of autistic parents, many of whom reported having "multiple conditions, as well as the autism" [215-AUTParent]. This pressure of "being the glue that holds the family together" [204-AUTParent] left them "just stuffed, and basically not able to function" [205-AUTParent]: "It felt like I was always required to be the eye in the cyclone and my mental health suffered terribly" [230-AUTParent].

Autistic adults and parents further reported that the negative effects on mental health were even greater because they felt *disconnected from the community* (subtheme 3.2) that usually offered them sustenance and informal support. For some people, the discussions on Facebook and other online groups had become "overwhelming, particularly watching people get themselves hit up into states about the coronavirus" [038-AUT]. Others noticed that community members had been interacting less: “people are getting more isolated or don’t feel like talking” [022-AUT].

This disconnection had broader consequences. Prior to the pandemic, many participants reported receiving some form of therapeutic services, especially psychiatric and psychological support. Many now highlighted that they *stopped accessing these services and support during the pandemic* (subtheme 3.3). Some participants found the shift to online or telehealth services to be “quite an easy transition” [009-AUT]. Most, though, reported intense difficulties. Families who needed “very practical hands-on support … that just hasn’t been possible” [234-AUTParent]. Other people commented that “all of our support people went into social isolation” [204-AUTParent], which meant that “all of a sudden overnight we lost them and all that kind of stuff … we had to go ‘no people’. That was really rough” [218-AUTParent]. Many people found it more difficult to access services and supports, including the ones with which they had engaged previously.

The loss of some services had dire consequences for some people. Participants reported trying to access therapeutic services through telehealth (online video or telephone), but swiftly stopped. One adult noted that “you couldn’t get through [to anonymous helplines], so many people calling” [043-AUT], while a parent reported that his “wife tried to call for help and she was on the phone for such a long time. But they did not answer… it drove her crazy” [347-NAParent]. Some people reported simply not hearing from professionals, who they “keep calling and calling” [330-NAParent] but who had since become “uncontactable” [214-AUTParent]. Young people consistently reported negative experiences with telehealth. One young person, who was admitted to acute psychiatric care four weeks into lockdown, also described:

> Before the outbreak, I had weekly psychology appointments and monthly psychiatrist appointments. As soon as it was not safe to go out, I stopped all my psychologist appointments, which was a bad call… because if it’s an online version of a medical appointment of any sort, I just dread it. And the dread is often worse than not doing the appointment [114-YP]

For parents of young children, who had been asked to switch to telehealth to continue therapy sessions during lockdown, they too reported negative experiences. One parent of a non-speaking autistic child told us: “Telehealth is something that you wouldn’t consider at all from my perspective. It wouldn’t work for our kids” [307-NAParent]. For some, familiarity and well-established prior relationship enabled continuity, but not always. Even established relationships with therapists, however, failed to ensure engagement: “the speech therapist came into kindergarten and he knows that’s a time where you just sit down and you work with that therapist one-on-one, but it just didn’t translate to the computer screen” [326-NAParent]. Fortunately, some children experienced continuity of care because “his psychiatrist was able to continue face-to-face (to accommodate her largely autistic clientele, many of whom did not want to use telehealth)” [224-AUTParent]. For the majority, however, it meant that their children were “not able to get these services currently. We just have to ride it out, so to speak” [312-NAParent].

It was not only children and young people who found telehealth so challenging. Autistic adults also reported that many (though not all) of their psychiatrist, psychologist, and counselling sessions had switched to online or over the phone. But adults also found it “really hard … because of the little delays of online communication” [013-AUT], “not being willing to be having those kinds of conversations having my kids home 24/7” [018-AUT], or because they felt that “it just lacks the humanity” [007-AUT]. Ultimately, many autistic young people and adults felt that their sessions have “to be face-to-face … I need that personal interaction” [020-AUT]. As one young person put it: “being there is a pretty big part for me, pretty big part of it” [115-YP].

Discussion

Influential theoretical accounts of autism emphasise diminished social motivation or social skills in autism (Baron-Cohen, 1995; Chevallier et al., 2012, p. 231; Dawson et al., 2005; see Jaswal & Akhtar, 2019, for critical discussion). Some versions of these accounts indeed suggest that autistic people fundamentally “lack the motivation or capacity to share things psychologically with others" (Tomasello et al., 2005, p. 723). If true, this would give reason to expect that autistic people might not respond to social isolation in an adverse way, and thus might have been adept at dealing with the COVID-related lockdown restrictions.

Our data from young autistic children and teenagers, autistic parents and other autistic adults do not support this view. While our participants did report some sense of release from the often-overwhelming demands of some conventional social interactions (e.g., the chatter of mums at the school gate, the pressure of extended family dinners), they did not report feeling "freed" from social interaction *per se*. Instead, they reported seriously missing much social contact, including existing friendships, everyday rhythms and routines and incidental social interactions. In line with Oomen et al.'s (2020) results, therefore, our findings suggest that autistic people felt a profound need for social contact during the lockdown.

Many of our participants reported significant psychological distress in themselves or their child(ren) during the initial lockdown, similar to the findings of other studies described above (Adams et al., 2021; Amorim et al., 2021; Asbury et al., 2020; Bal et al., 2021; Oakley et al., 2020; White et al., 2021). Our data also suggest that this distress may have resulted, at least in part, from the absence of social interaction. Participants reported that being unable to enjoy their usual social interactions was extremely challenging, even if the use of social media and other digital technologies mitigated some negative effects. Feelings of loneliness appear to have intensified rapidly for some, as they are widely acknowledged to do in the general population (Bzdok & Dunbar, 2020; Orben, Tomova, & Blakemore, 2020), and appear to have contributed to intense mental health difficulties, at least for some. These findings echo those of Oomen et al. (2020), who found that the loss of social contact was the most often reported difficulty for both autistic and non-autistic adults as a result of the COVID-related restrictions.

The cost of loneliness and isolation on mental and physical health in more 'normal' times is well established (Holt-Lunstad et al., 2015). Our findings demonstrate that the autistic experience during the pandemic – for adults, children, young people and parents – was no different in this regard to the non-autistic experience, as reported elsewhere (Loades et al., 2020). Our findings support recent work highlighting the potential effects of loneliness on depression and thoughts of self-harm in autistic adults (Hedley et al., 2018). Further research is thus urgently required in order to discover the specific ways in which autistic people can be enabled to foster mutually-supportive social connections on their own terms in future.

In considering how such social connections can be maintained, it is also important to note that the reported negative impacts on mental health were further compounded by disruption to therapeutic services. Even in pre-COVID times, autistic people report a significantly higher number of unmet support needs than the general population (Camm-Crosbie et al., 2018), and struggle to access appropriate support and services, especially for mental health problems (Crane et al., 2018; Maddox et al., 2020). COVID-19 has intensified those difficulties (Oakley et al., 2020). The rapid introduction of telehealth services for our Australian participants was intended to grant greater access to mental health supports. Participants welcomed these services in principle, but practical experiences were underwhelming. Most found that telehealth was not a sufficient alternative to face-to-face service delivery (see also Masi et al., 2021). Interestingly, Bal et al. (2021) reported that, although many autistic adults recognised the benefit of online services early on in the pandemic, those who did not were more likely to experience greater mental health distress almost two months later. Together, these findings are an important reminder that despite the understandable enthusiasm for technological innovations among many clinicians and autistic advocates, they should not be thought of as a panacea for autistic people. Further research is required to test the acceptability of telehealth across a range of formats (phone, video, email/text chat), therapeutic services (e.g., general practice, psychology and psychiatry services, speech and language therapy, occupational therapy, behavioural therapy) and recipients (autistic adults, children of different ages, parents), including those who use non-traditional forms of communication. Critically, more research is needed to demonstrate the *effectiveness* of telehealth therapies for autistic people (see Sutherland, Trembath, & Roberts, 2018, and Oakley et al., 2021, for discussion).

As technological change continues apace, it is also important that significant attention continues to be paid to what can be described as the "relational dynamics" of care and support (Cottam, 2018) and of the affordances of real-world physical interactions. Our findings support the view that face-to-face support structures are critical for autistic people's wellbeing, at least in part because of their ability to provide incidental social interaction. Similarly, these results give credence to the suggestion that continuity of care is vitally important to autistic people and their families as it enables social contacts and relationships that often come from service delivery. When such face-to-face provision is restricted, we therefore believe that guaranteed, regular, scheduled and individualized catch-ups with key workers and peers could be vital to wellbeing.

Limitations

Our study is not without its limitations. First, these findings may not be fully representative of the autistic population. The sample included a significant proportion of well-educated participants from white racial/ethnic backgrounds, and those who were willing and able to share their views and experiences. Indeed, our recruitment methods – prompted by the restrictions of the time – relied on people being active on social media and may, therefore, have primarily reached those with more established social networks. These methods may also have led to a bias toward people who used traditional forms of communication and were not accessing more specialised supports. As such, the extent of the hardships may well be an *underestimate* of mental health distress felt elsewhere. That said, our study is large for a qualitative study, sampled individuals across a wide age range (12 – 69 years) with converging results across informants, and included the voices of those (autistic young people, autistic parents) who are all too seldom heard in autism research.

Second, and relatedly, the gender distribution of our adult sample (more women than men) is different to population norms for diagnosis (as more men receive a diagnosis; Loomes et al., 2017). Although this is not unusual for online studies like this one (e.g., Arnold et al., 2019; Kapp et al., 2013; Kenny et al., 2016), it may have influenced the pattern of findings reported herein. There is some suggestion in the literature that autistic girls and women show a greater desire for social contact than autistic boys and men (e.g., Head et al., 2014; Lai et al., 2015; Sedgewick et al., 2016), although others suggest that these findings are actually due to the social expectations imposed on girls and women (see Kreiser & White, 2016, for discussion). In any case, we found a similar pattern of findings across all groups in our study, including among our autistic young people and in parents' reports of their autistic children, where the gender distribution was more similar to existing prevalence estimates (Loomes et al., 2017).

Third, it should be noted that the majority of our participants came from Australia, whose state governments' stay-at-home orders were stricter than many other countries, and whose citizen compliance rates were unusually high (Chang et al., 2020). It is possible, therefore, that the reported social isolation was felt more deeply among this sample than it would have been elsewhere, although the themes identified herein were also reflected in our 14 non-Australian participants' interviews, as well as Oomen et al.'s (2020) European participants.

Conclusion

Autistic children and young people, adults and parents alike reported being disoriented by the loss of everyday routines as a result of the COVID-19 restrictions and insisted that they most missed *social* life, including incidental connections. The current in-depth, interview-based research reveals, therefore, that many previous theoretical accounts have under-appreciated autistic people's need for human interaction and the extent to which social isolation can play a role in autistic people's mental health distress (Cassidy et al., 2020). We need, as a result, a strategic research program, designed in partnership with the autistic community (Fletcher-Watson et al., 2018; Nicolaidis et al., 2019) to ensure that autistic people's social needs do not continue to be overlooked in these times of uncertainty or beyond.

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Table 1. Participant characteristics.

	Autistic adults (n=44)	**Parents of autistic children (n=84)**		**Young people (n=16)**
		Autistic parents (n=35)	**Non-autistic parents (n=49)**	
	Mean (SD) Range or N (%)			
Age (years)	39.10 (11.50) 23.22–69.35	42.69 (5.58) 32.88–54.48	44.06 (9.14) 23.58–65.45	14.95 (2.08) 12.14–18.41
Age at autism diagnosis (years)	31.46 (13.89) 2–64	42.92 (6.63) 28–52	NA	8.38 (3.72) 2–16
Interview duration (min)	53.41 (22.92) 15.20–99.44	56.56 (17.81) 21.80–86.30	51.89 (18.23) 16.50–110.40	28.81 (11.02) 19.20–50.40
Gender				
Woman/girl[a]	28 (64%)	32 (91%)	45 (92%)	5 (31%)
Man/boy[b]	12 (27%)	2 (6%)	4 (8%)	8 (50%)
Non-binary	3 (7%)	1 (3%)	0	2 (12%)
Other	1 (2%)	0	0	1 (6%)
Country of residence				
Australia	34 (77%)	34 (97%)	47 (96%)	15 (94%)
New Zealand	1 (2%)	0	0	0
Philippines	1 (2%)	0	0	0
UK	7 (16%)	1 (3%)	1 (2%)	1 (6%)
USA	1 (2%)	0	1 (2%)	0
Predominant racial/ethnic background				
Australian Aboriginal	1 (2%)	0	1 (2%)	0
Chinese	1 (2%)	0	3 (6%)	1 (6%)
East Asian	0	0	1 (2%)	0
Mixed	2 (4%)	3 (8%)	3 (6%)	0
White Australian/New Zealand	6 (14%)	8 (23%)	5 (10%)	1 (6%)

White European	30 (68%)	24 (68%)	31 (63%)	12 (75%)
White Other	1 (2%)	0	5 (10%)	2 (12%)
Prefer not to say	3 (7%)	0	0	0
Living arrangements				
Alone	18 (41%)	0	1 (2%)	–
With partner only	14 (32%)	0	5 (10%)	–
With partner & children	1 (2%)	26 (74%)	32 (65%)	–
With children only	1 (2%)	6 (17%)	9 (18%)	–
With relatives	6 (14%)	3 (8%)	2 (4%)	–
With friends	4 (9%)	0	0	–
Highest qualification				
Completed primary school	0	1 (3%)	0	–
Completed Year 10	3 (7%)	1 (3%)	2 (4%)	–
Completed high school	6 (14%)	4 (11%)	3 (6%)	–
Vocational training	11 (25%)	4 (11%)	6 (12%)	–
Undergraduate degree	12 (27%)	10 (28%)	12 (24%)	–
Postgraduate degree	12 (27%)	15 (43%)	26 (53%)	–
Pre-COVID-19 occupational status				
Part-time employment	10 (23%)	5 (14%)	14 (28%)	–
Full-time employment	11 (25%)	8 (23%)	14 (28%)	–
Self-employed	7 (16%)	5 (14%)	5 (10%)	–
Studying	6 (14%)	4 (11%)	4 (8%)	–
Full-time parent	2 (4%)	11 (31%)	10 (20%)	–
Unable to work due to disability	2 (4%)	2 (6%)	0	–
Unemployed & seeking work	5 (11%)	0	1 (2%)	–
Retired	1 (2%)	0	0	–
Prefer not to say	0	0	1 (2%)	–
Co-occurring conditions[c]				

ADHD	14 (32%)	14 (40%)	3 (6%)	5 (31%)
Anxiety disorders	24 (54%)	19 (54%)	12 (24%)	9 (56%)
Autoimmune disorders	3 (7%)	8 (23%)	6 (12%)	0
Bipolar disorder	6 (14%)	0	1 (2%)	–
Chronic fatigue syndrome	2 (4%)	1 (3%)	0	0
Chronic pain	6 (14%)	9 (26%)	3 (6%)	0
Depression	26 (59%)	23 (66%)	12 (24%)	5 (31%)
Drug/alcohol dependence	2 (4%)	0	0	–
Dyslexia	2 (4%)	2 (6%)	1 (2%)	1 (6%)
Dyspraxia	1 (2%)	0	0	0
Eating disorders	6 (14%)	3 (8%)	2 (4%)	2 (12%)
Epilepsy	1 (2%)	0	0	0
Gastrointestinal issues	8 (18%)	14 (40%)	5 (10%)	0
Intellectual Disability	2 (4%)	0	0	0
OCD	5 (11%)	1 (3%)	0	1 (6%)
Personality disorders	5 (11%)	0	1 (2%)	–
PTSD	11 (25%)	11 (31%)	2 (4%)	0
Schizophrenia disorders	1 (2%)	0	0	–
Sleep disorders	11 (25%)	6 (17%)	4 (8%)	4 (25%)

Notes. Data are mean (SD; range) or n (%). Percentages may not sum to 100% due to rounding issues. NA=not applicable. [a]Included transgender women; [b]Included transgender men; [c]Participants could select all options that applied to them. Percentages therefore do not add to 100.

Table 2. Characteristics of the autistic children, as reported by parents.

	Autistic parent group (n=35)	Non-autistic parent group (n=49)	Total (n=84)
	Mean (SD) Range or N (%)		
Total number of autistic children	n=55	n=61	n=116
Number of autistic children in family			
One child	17 (48%)	41 (84%)	58 (50%)
Two children	16 (46%)	7 (14%)	23 (40%)
Three children	2 (6%)	0	2 (5%)
Six children	0	1 (2%)	1 (5%)
Children's age	10.21 (4.04) 3.98–25.33	11.07 (5.66) 3.30–29.11	10.54 (4.85) 3.30–29.11
Children's gender			
Girl	22 (40%)	13 (21%)	35 (30%)
Boy	30 (54%)	47 (77%)	77 (66%)
Non-binary	3 (5%)	1 (2%)	4 (3%)
Co-occurring diagnoses			
None	14 (25%)	10 (16%)	24 (21%)
ADHD/ADD	27 (49%)	16 (26%)	43 (37%)
Anxiety disorders	29 (53%)	23 (38%)	52 (45%)
Cerebral palsy	1 (2%)	0	1 (1%)
Depression	3 (5%)	8 (13%)	11 (9%)
Dyslexia	7 (13%)	1 (2%)	8 (7%)
Dyspraxia	5 (9%)	2 (3%)	7 (6%)
Eating disorders	1 (2%)	4 (6%)	5 (4%)
Epilepsy	1 (2%)	2 (3%)	3 (2%)
Hearing loss	0	1 (2%)	1 (1%)
Intellectual disability	1 (2%)	13 (21%)	14 (12%)
PTSD	2 (4%)	0	2 (2%)
Sleep disorders	6 (11%)	7 (11%)	13 (11%)
Tourette Syndrome	0	1 (2%)	1 (1%)
Vision impairment	1 (2%)	0	1 (1%)
Current school setting			
Mainstream with no extra support	16 (29%)	11 (18%)	27 (23%)
Mainstream with extra support	21 (38%)	30 (49%)	51 (44%)
Autism-specific class within a mainstream school	1 (2%)	3 (5%)	4 (3%)
General disability class within a mainstream school	0	3 (5%)	3 (2%)
Home-schooled	5 (9%)	1 (2%)	6 (5%)
Special school	0	4 (6%)	4 (3%)
Other (e.g., mixed enrolment)	4 (7%)	4 (6%)	8 (7%)
Vocational college	0	0	0
Not applicable	8 (14%)	5 (8%)	13 (11%)

Note. The parent of one of the 16 young people was not interviewed; therefore, details of 15 of the 16 young person participants are included in this table.