


SHORT REPORT

Psychological distress among caregivers raising a child with autism spectrum disorder during the COVID-19 pandemic

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Abstract

The COVID-19 pandemic may disproportionately impact parents of children with autism spectrum disorder (ASD). Loss of services and supports, heightened fears about increased infection rates, and disruption of daily routines likely adversely affect the well-being of children with ASD and their families. The goal of this study was to examine differences in psychological distress—as defined by symptoms of anxiety, depression, loneliness, and hyperarousal—between parents raising a child with ASD and parents in the US as a whole during the early stages of the pandemic (March–April 2020). Parents raising a child with ASD ($n = 3556$) were recruited through SPARK, a national ASD research registry, whereas a representative sample of parents in the US ($n = 5506$) were recruited from the Pew Research Center's American Trends Panel. All data were captured via online surveys. Descriptive statistics and multivariable logistic regressions examined psychological distress at the item and summary score level. Parents of children with ASD reported higher levels of overall psychological distress (48% vs. 25%; aOR = 1.60, 95% CI: 1.32, 1.84, $p < 0.001$). Hyperarousal, or feelings of panic when thinking about COVID-19, was particularly prevalent among parents of children with ASD compared to parents in the US (25% vs. 9%; aOR = 2.38, 95% CI: 1.83, 3.07, $p < 0.001$). Findings highlight the importance of considering the policies and practices that contribute to poor mental health in parents, particularly those raising a child with ASD, to ensure mental health services remain accessible.

Lay Summary

This study examined the mental health of parents raising a child with ASD during the early stages of the COVID-19 pandemic. Results demonstrated substantially higher levels of psychological distress, particularly those related to feelings of panic, among parents raising a child with ASD when compared to parents in the US as a whole. These data suggest the need for ensuring mental health services are accessible to parents, particularly those raising a child with ASD, during and after the pandemic.

INTRODUCTION

The COVID-19 pandemic has taken a toll on the mental health of Americans (Hologue, Badillo-Goicoechea, et al., 2020; Hologue, Kalb, et al., 2020). For those with a neurodevelopmental disability, such as autism spectrum disorder (ASD), and their loved ones, the impact may be

especially acute (Constantino et al., 2020; Manning et al., 2020). Lack of access to education and therapeutic services, loss of caregiving support, and disruptions to daily routines are likely to have directly impacted the well-being of children with ASD and their parents. There are also serious concerns about the increased risk of COVID-19 exposure among this population. Children

with ASD may have difficulty adhering to basic preventive measures such as mask-wearing, social distancing, and hand hygiene. COVID-19 testing methods, especially those that employ nasal swabs, are likely difficult to implement given the sensory issues intrinsic to ASD. For these reasons, parents raising a child with ASD may be at heightened risk for experiencing significant psychological distress during the pandemic. Psychological distress is a general construct that indicates the stress and demands of daily life have surpassed an individual's coping mechanisms (Veit & Ware, 1983). It reflects a range of symptoms and states, often closely aligned with anxiety and depression, from mild levels of mental distress to severe psychiatric conditions (McLachlan & Gale, 2018).

Prior to the pandemic, several studies have shown parents raising a child with ASD are at increased risk of a mental health disorder, particularly anxiety and depression, when compared to the general population (Schnabel, Youssef, et al., 2020). This risk is multifactorial. Genetic liability, developmental characteristics of the child, caregiving stress, social stigma, and procuring as well as paying for the child's healthcare all place substantial demands on parents (Falk et al., 2014; Hsiao, 2016). This context, coupled with the pandemic, places parents in a perfect storm for experiencing psychological distress.

At present, little data exists on the mental health of parents raising a child with ASD during the COVID-19 pandemic in the United States. The goal of this study was to fill that gap by comparing psychological distress—as defined by symptoms of anxiety, depression, loneliness, and hyperarousal—during the pandemic between parents of children with ASD and a nationally-representative sample of US parents.

METHODS

Sample

Data for this population-based study came from parents across two disparate samples. Parents ($n = 3556$) raising a child with ASD were recruited from the Simons Foundation Powering Autism Research project (SPARK; Feliciano et al., 2018). SPARK is a national ASD genotyping project that recruits families from 31 academic medical centers across the US. To date, over 70,000 families have enrolled in SPARK. Once families enroll, they are offered the opportunity to continue hearing about and engaging in prospective research opportunities through their online research registry. SPARK requires respondents to have personal access to devices with an internet connection to complete online surveys. To be included in the present study, parents must: (1) Be >17 years of age; (2) Report not having ASD themselves; (3) Have at least one child with ASD <18 years of age; and (4) Report at or above the validated cutoff for ASD (>12) via the Lifetime Version of the Social Communication

Questionnaire for their child with ASD (Eaves et al., 2006). The SPARK questionnaire was fielded between March 20th–April 3rd, with a 13% response rate.

Data from parents ($n = 5506$) in the US as a whole came from the Pew Research Center's American Trends Panel (ATP). The ATP is an online survey panel constructed from a random sample of US households (Pew Research Center & Inquiries, 2021). The ATP panel is developed based on best practice guidelines set forth by the American Association for Public Opinion Research (Task Force on Address-based Sampling, 2016). Further details on panel construction can be found here: <https://www.pewresearch.org/methods/u-s-survey-research/american-trendspanel/>. ATP provides a tablet (with an internet connection) to those who did not have the resources to complete the survey online. To be included in the present study sample, respondents who are >17 years of age must report being the parent of at least one child <17 years of age. The ATP survey was fielded between March 19th–24th, with a 75% response rate.

Measures

Psychological distress

The SPARK and ATP surveys fielded the same measure of psychological distress. This measure included four items that were drawn from reliable and valid measures, including the Center for Epidemiologic Studies Depression Scale, the Generalized Anxiety Disorder-9, and the Impact of Event Scale-Revised (Holingue, Badillo-Goicoechea, et al., 2020). Using a 4-point Likert response, each respondent was asked how often in the past 7 days they: (1) “felt nervous, anxious, or on edge”; (2) “felt depressed”; (3) “felt lonely”; and (4) had “physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart when thinking about their experience with the COVID-19 outbreak” (hereafter referred to as hyperarousal). Response options for these items included “rarely or none of the time (less than 1 day)”; “some or a little of the time (1–2 days)”; “occasionally or a moderate amount of time (3–4 days)”, or “most of the time (5–7 days)”. The measure was internally consistent across the ATP and SPARK surveys ($\alpha = 0.77$). Internal consistency, measured via Cronbach's alpha, is an indicator of reliability (Eisinga et al., 2013). Each item was dichotomized as present vs. absent when the symptoms lasted at least 3 days over the past week. Overall psychological distress was identified when two or more symptoms were present for at least 3 days a week (Holingue, Kalb, et al., 2020).

Sociodemographics and psychiatric history

Basic informant sociodemographics were gathered across both SPARK and ATP surveys. This included informant

age (in years), sex (male/female), education (less than high school, high school, Associate's degree or some college, Bachelor's degree, Graduate degree), marital status (never married, married, separated or divorced, other), race/ethnicity (Black, non-Hispanic; Hispanic; White, non-Hispanic; other), metropolitan area, and US census region. Both surveys also included a single, dichotomous item assessing history of a mental health condition ("Have you ever been told by a doctor or other healthcare provider that you have a mental health condition?"). Only SPARK included measured characteristics of the child (child age, sex).

Analysis

Sociodemographics and psychological distress items were reported descriptively across surveys. A series of survey-weighted regression models individually examined differences in sociodemographics, psychological distress items, overall distress between parents raising a child with ASD (SPARK), and parents in the US (ATP) as a whole. For the psychological distress items and overall score, a survey-weighted multivariable logistic regression model was employed. Multivariable models adjusted for parental education, age, sex, race/ethnicity, marital status, metropolitan area, US region, and history of a prior mental health condition. Survey weights for the ATP sample allow for inferences to be made to adult parents in the US. Weights were set to 1 for SPARK given the convenience sampling.

Overall, there was very little missing data (<2% for all variables). As such, complete case analysis was employed. All analyses were performed in R Studio (version 1.1.383) (RStudio, 2015) with R version 3.6. (R Development Core Team, 2019). Given the multiple statistical testing, the threshold for statistical significance was lowered using a Bonferroni correction. With 13 total tests, $p < 0.004$ was considered statistically significant. This study was approved by the Johns Hopkins School of Medicine Institutional Review Board.

RESULTS

Table 1 displays sample characteristics across parents raising a child with ASD (SPARK) and parents in the US as a whole (ATP). Parents raising a child with ASD were less likely to be male (5% vs. 39%), and more likely to be White Non-Hispanic (75% vs. 56%), have a higher level of education (e.g., Bachelor's, 28% vs. 18%, or Graduate degree, 23% vs. 16%), and have a prior mental health condition (50% vs. 17%) compared to parents in the US (all $p < 0.001$). Greater psychological distress was higher among parents raising a child with ASD, as seen in Table 1. This includes experiencing symptoms of anxiety (65% vs. 45%), depression (33% vs. 22%), loneliness (28% vs. 15%), and hyperarousal (25% vs. 9%) for at least

3 days a week; overall distress was elevated as well (48% vs. 25%) (all $p < 0.001$).

Results for the multivariable models are shown in Table 2. After adjustment for informant age, race, sex, education, marital status, metropolitan area, geographic region, and prior mental health condition, psychological distress items (anxious, lonely, hyperarousal) and overall distress were elevated among parents raising a child with ASD when compared to parents in the US as a whole (all $p < 0.001$). Depression was not statistically significant after adjusting for multiple testing.

DISCUSSION

Our findings demonstrate significant psychological distress among parents raising a child with ASD during the early months of the COVID-19 pandemic. Almost half (48%) reported substantial psychological distress, a proportion significantly greater than parents in the US as a whole (25%). This large discrepancy remained after adjusting for numerous covariates, including history of a prior mental health condition. These data suggest clinicians, researchers, and policymakers should consider the mental health of parents of children with ASD as the pandemic unfolds. This finding may extend to parents of children and/or adults with neurodevelopmental disabilities as a whole.

Fortunately, there are several mental health services available for parents of children with ASD (Catalano et al., 2018). However, the COVID-19 pandemic and associated restrictions will likely make access to these services more difficult. It is important these services remain affordable and accessible, particularly for families from under-resourced backgrounds. Telehealth presents an opportunity to extend these services to families during and after the pandemic. Further research is needed to ensure these approaches remain efficacious when employed virtually.

Hyperarousal was especially elevated among parents of children with ASD. This survey item assessed feelings of panic and the presence of somatic symptoms when thinking about COVID-19. Positive responses to this item could indicate vulnerability to COVID-related trauma. Prior research has suggested greater levels of trauma, particularly Post Traumatic Stress Disorder, in parents of children with ASD who have severe challenging behavior (Schnabel, Hallford, et al., 2020; Stewart et al., 2020). Unfortunately, no measures of child-level behavior were available in the present study. Future work is needed to understand if the increased levels of hyperarousal symptoms are related to increases in child externalizing behavior during COVID-19, increased COVID-19 infections in the child and/or family, or reflective of increased fears as a result of COVID-related stress.

It is important to recognize the substantial mental health burden among the parents in the US as a whole. More than one in four reported psychological distress

TABLE 1 Differences in demographics and psychological distress between parents raising a child with ASD (SPARK) and parents in the US (ATP)

	Parents in US population (ATP)	Parents of children with ASD (SPARK)	<i>p</i> value
Total (<i>N</i>)	3035	5506	—
Parent sex (<i>N</i> , %)			
Female	1851 (61)	3365 (95)	<0.001
Male	1183 (39)	191 (5)	
Informant race (<i>N</i> , %)			
Black, non-Hispanic	364 (12)	220 (4)	<0.001
Hispanic	667 (22)	936 (17)	
White non-Hispanic	2003 (56)	4130 (75)	
Other/Refused/Missing			
Informant age (<i>N</i> , %)			
18–29	486 (16)	220 (4)	<0.001
30–49	2094 (69)	4680 (85)	
50–64	425 (14)	606 (11)	
65+	43 (1.4)	20 (<1)	
Informant level of education (<i>N</i> , %)			
Less than high school	243 (8)	110 (2)	<0.001
High school	911 (30)	606 (11)	
Associates degree or some college	941 (31)	2037 (37)	
Bachelor's degree	546 (18)	1542 (28)	
Graduate degree	486 (16)	1266 (23)	
Metropolitan area			
Metropolitan	2610 (86)	4625 (84)	0.11
Nonmetropolitan	425 (14)	881 (16)	
Census division			
New England	121 (4)	275 (5)	0.33
Middle Atlantic	364 (12)	550 (10)	
East North Central	425 (14)	716 (13)	
West North Central	182 (6)	606 (11)	
South Atlantic	637 (21)	1046 (19)	
East South Central	182 (6)	385 (7)	
West South Central	364 (12)	441 (8)	
Mountain	334 (11)	385 (7)	
Child Age (M, SD)	N/A	10.2 (4.0)	—
Child Sex (<i>N</i> , %)			
Male	N/A	4436 (81)	—
Female	N/A	1070 (19)	
SCQ Total (M, SD)	N/A	24.0 (5.8)	—
Informant marital status (<i>N</i> , %)			
Never married	334 (11)	826 (15)	<0.001
Married	2003 (66)	3854 (70)	
Divorced/Separated	334 (11)	826 (15)	
Other/Refused	395 (13)	26 (<1)	
History of a mental health Condition (<i>N</i> , %)			
No	2519 (83)	2753 (50)	<0.001
Yes	516 (17)	2753 (50)	

(Continues)

TABLE 1 (Continued)

	Parents in US population (ATP)	Parents of children with ASD (SPARK)	<i>p</i> value
Psychological distress items (<i>N</i> , %)			
Anxious	1366 (45)	3579 (65)	<0.001
Depressed	668 (22)	1817 (33)	<0.001
Lonely	455 (15)	1542 (28)	<0.001
Hyperarousal	273 (9)	1377 (25)	<0.001
Overall psychological distress score	759 (25)	2643 (48)	<0.001

Note: ATP (American Trends Panel), weighted to be representative of the US population; SPARK (Simmons Foundation Powering Autism Research), an online autism research registry; SCQ (Social Communication Questionnaire); Response options for psychological distress items include “rarely or none of the time (less than 1 day)”; “some or a little of the time (1–2 days)”; “occasionally or a moderate amount of time (3–4 days)”; or “most or all of the time (5–7 days)”. N/A = Not Available.

TABLE 2 Results of individual multivariable regression models evaluating differences in psychological distress between parents of children with ASD compared to parents in the US

Outcome	Odds ratio	95% CI	<i>p</i> value
Anxious	1.37	1.18, 1.59	<0.001
Depressed	1.22	1.02, 1.45	0.02
Lonely	1.57	1.28, 1.91	<0.001
Hyperarousal	2.38	1.83, 3.07	<0.001
Overall psychological distress score	1.60	1.32, 1.84	<0.001

Note: Odds ratios adjusted for education, race/ethnicity, marital status; ATP (American Trends Panel), weighted to be representative of the US population; SPARK (Simmons Foundation Powering Autism Research), an online autism research registry.

during the early portion of the pandemic. This further reinforces the need for mental health services to be accessible and affordable. Prevention efforts, including maintaining physical health, sleep hygiene, and social contact (under guidelines by the Centers for Disease Control), will be especially critical for those without a history of a mental health condition. That is, individuals who are treatment naïve may face additional barriers to service engagement, including stigma and difficulty navigating the healthcare system. However, as Cosgrove and Herrawi (2021) articulate, it’s critical we do not conflate access to mental health services with health equity. Such thinking ignores the underlying social and structural issues which contribute to poor mental health and exacerbates inequities during the COVID-19 pandemic. Advancing policies and practices, which target the cause of mental distress and long-standing inequities, is needed.

There are several strengths and limitations to the present study. In terms of strengths, the study sample was large and national. We were able to adjust for potentially important confounders, including a history of mental health conditions among parents. Findings are novel and important to both policy and practice. However, the study design was cross-sectional and the measurement was limited, especially in terms of child and household characteristics (e.g., number of children in the home). For instance, it would have been preferable to remove children with ASD from the national sample. This could not be done because no data were available on child diagnosis in the ATP survey.

However, this likely had little effect on the findings given the population prevalence of ASD is relatively low (1.85%; Maenner et al., 2020). If anything, this limitation likely results in an underestimation of the observed associations. The SPARK sample was also recruited via convenience sampling. The low response rate, in particular, was a concern. This raises concerns about selection bias and/or lack of generalizability. Finally, the observational nature of this study limits the ability to decisively conclude the findings are solely attributable to raising a child with ASD. There may be other factors, which could have influenced the findings, such as a lack of access to resources and supports (Cosgrove & Herrawi, 2021).

In summary, this study found a higher prevalence of psychological distress among parents raising a child with ASD compared to parents in the US as a whole. It is important that mental health services, particularly those that address feelings of panic, remain accessible during and after the pandemic for all populations, particularly parents raising a child with ASD.

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