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COVID and autism lessons learnt and future directions for research

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Edited by
Michaela DuBay, Cecilia Montiel Nava and
Georgina Perez Liz

Coordinated by
Casara Jean Ferretti

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COVID and autism 2023: Lessons learnt and future directions for research

Topic editors
Michaela DuBay — University of Virginia, United States
Cecilia Montiel Nava — The University of Texas Rio Grande Valley, United States
Georgina Perez Liz — Drexel University, United States

Topic coordinator
Casara Jean Ferretti — Albert Einstein College of Medicine, United States

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Editorial: COVID and autism 2023: lessons learnt and future directions for research

Georgina Perez Liz[1]*, Michaela DuBay[2] and Cecilia Montiel-Nava[3]

[1]A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA, United States, [2]School of Education and Human Development, University of Virginia, Charlottesville, VA, United States, [3]Department of Psychological Science, College of Liberal Arts, The University of Texas Rio Grande Valley, Edinburg, TX, United States

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Editorial on the Research Topic
COVID and autism 2023: lessons learnt and future directions for research

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Antonio M. Persico,
University of Modena and Reggio Emilia, Italy

*CORRESPONDENCE
Georgina Perez Liz
gmp69@drexel.edu

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Over four years ago, the coronavirus pandemic sent many countries into national lockdowns, severely restricting social interaction and professional, academic, health, and leisure activities alike. The virus itself infected hundreds of millions of people, yet the wide ranging indirect impacts were felt almost universally. Those with existing conditions were impacted in unique ways. Globally, autistic people and their caregivers reported significant reduction in mental health (1–3), and reductions in service access which led to increases in challenging behaviors (4) during the acute stages of the pandemic. Impacts of the later stages of the pandemic, including phases of masking requirements, continued restrictions to non-essential social interactions, new waves of variants, and continued risk to physical health are still being explored (5).

Fully understanding both the acute and long-term impacts of the COVID-19 pandemic on the lives of autistic individuals and their caregivers will help to inform preparedness and response to future public health emergencies. This Research Topic aims to highlight evidence on how the COVID-19 pandemic has affected and continues to affect autistic individuals globally as well as to provide insights into research and interventions on how this can be tackled going forwards.

We anticipate that research presented will be able to translate to best practice applications in clinical and public health settings. Within this Research Topic, we present a range of articles including seven original research articles, one brief research report, and one opinion article. This Research Topic provides new evidence from across countries and continents on what we have learned about COVID-19 and autism since the beginning of the pandemic, including the physical and mental impacts of COVID-19 on the autistic population, the effects of lockdowns and social distancing on autistic individuals, and the impact that these aspects had and continue to have on care provided for autistic individuals. Perspectives are presented from Argentina, Brazil, Chile, the Dominican Republic, Italy, Mexico, Poland, Portugal, Qatar, Saudi Arabia, Uruguay, Venezuela, and the United States, which allows for a broad representation of global impacts.

The articles presented in this Research Topic highlighted important challenges faced by the autistic population, along with areas of opportunity to improve care during global health emergency situations. Several key themes emerged. Firstly, service delivery disruptions and access challenges were identified across essential services and supports for the autistic community. These included special education, speech and occupational therapies, applied behavior analysis, and mental health services (Gatica-Bahamonde et al.; Pokoski et al.; Tsai and Bhat). School closures and transition to remote learning were particularly challenging, and recovery from these situations continues to be slow and unequal across different demographic groups (Tsai and Bhat).

Secondly, caregivers of autistic children and adults faced increased stress and burden (Sousa et al.; Pokoski et al.), sometimes resulting in measurably poor mental health outcomes. In researching challenges and difficulties, we aimed to present studies that also discussed areas of strength, such as the study by Sousa et al., which found that family cohesion was a key protective factor against caregiver depression.

Thirdly, reports of behavioral and emotional challenges in the autistic population were a ubiquitous finding (Gatica-Bahamonde et al.; Pokoski et al.). Changes to routines and reduced access to services likely exacerbated these issues. Eating behaviors and routines were also areas negatively impacted by the COVID-19 pandemic, as reported by caregivers (Alharbi).

Fourthly, we have also learned that there were important disparities in the impact of the COVID-19 pandemic, and the importance of evaluating specific variables according to the research context. Pokoski et al. found that families of lower socioeconomic status, racial/ethnic minorities, and those in rural areas experienced greater service disruptions and financial distress. Tsai and Bhat also noted disparities in service access and recovery based on age, income, race/ethnicity and geographic location. In contrast, Alshaban et al. included hired help in the home as an analysis variable of the measured outcomes, since it is relevant in the cultural context of Qatar.

Finally, the rapid shift to telehealth and remote service delivery, from screening to intervention, presented both challenges and opportunities. While some services like screening adapted well to virtual formats (Gatica-Bahamonde et al.), others, such as occupational therapy, were more difficult to deliver remotely (Tsai and Bhat).

Although the World Health Organization (WHO) declared the end of the Public Health Emergency of International Concern (PHEIC) status for COVID-19 on May 5, 2023 (6) knowledge related to its impact in the life of people around the globe is still being uncovered. COVID-19 is no longer considered a global health emergency, though it remains a concern and requires ongoing management and vigilance. Lockdown measures, transition to online educational and health related services or their suspension, among others, were particularly challenging for autistic individuals and their families (7).

The articles in this Research Topic have cultivated reimagination of the challenges and possible solutions to the needs of autistic people, and highlight the significant impact that sudden changes in routine and access to services can have on the mental health of autistic individuals. As research shows disruptions in daily routines and reduced access to essential services during the pandemic exacerbated stress, anxiety, and other mental health issues among autistic individuals (Bieczek et al.; Montenegro et al.).

Moving forward, professionals and families can leverage these insights to better prepare for unforeseen situations. Implementing strategies such as maintaining as much routine as possible, utilizing virtual support services, and creating structured plans for potential disruptions can mitigate adverse mental health effects (Failla et al.; 8). Additionally, developing clear communication channels and providing social stories or visual schedules can help autistic individuals understand and adapt to changes, reducing anxiety and promoting stability (9). By applying these lessons learned during the pandemic, professionals and families can enhance their resilience and readiness for future interruptions or health crises.

Having learned from the experiences of adjusting services and measuring mental health issues in the autistic community across the globe, future research should focus on developing and evaluating interventions specifically designed to support autistic individuals and their families during times of disruption and crisis. For instance, more studies could explore the effectiveness of telehealth services in providing care starting at early detection, and continuous support and therapy, examining which modalities are most beneficial (10). In this way, when autistic individuals need to transition to this modality of service, they could have robust and evidence-based alternatives. Additionally, longitudinal research is needed to understand the long-term mental health impacts of pandemic-related disruptions on autistic individuals, particularly in terms of resilience and coping mechanisms (11). Investigating the role of personalized, adaptive routines and the use of technology to create virtual support networks may also provide valuable insights (12).

Furthermore, it is crucial to include the perspectives of autistic individuals and their families in research to ensure that interventions are tailored to their specific needs and preferences (13). By addressing these areas, future research can contribute to the development of more effective strategies to support the mental health and well-being of autistic individuals of all ages, abilities, and nationalities, during unforeseen circumstances.

Author contributions

GP: Conceptualization, Data curation, Writing – original draft, Writing – review & editing. MD: Conceptualization, Data curation, Writing – original draft, Writing – review & editing. CM: Conceptualization, Data curation, Writing – original draft, Writing – review & editing.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Where I am from matters: factors influencing behavioral and emotional changes in autistic individuals during COVID-19 in Latin America

María Cecilia Montenegro[1]*, Ana C. Ramírez[1], Juventino Hernandez Rodriguez[1], Bianca T. Villalobos[1], Gabriela Garrido[2], Cecilia Amigo[2], Daniel Valdez[3], Natalia Barrios[4], Sebastián Cukier[4], Alexia Rattazzi[4], Analía Rosoli[5], Ricardo García[6], Cristiane S. Paula[7], Georgina Pérez Liz[8] and Cecilia Montiel-Nava[1]

[1]Department of Psychological Science, University of Texas Rio Grande Valley, Edinburg, TX, United States, [2]Universidad de la República, Montevideo, Uruguay, [3]Facultad Latinoamericana de Ciencias Sociales (FLACSO), Ayacucho, Argentina, [4]Programa Argentino para Niños, Adolescentes y Adultos con Condiciones del Espectro Autista (PANAACEA), Buenos Aires, Argentina, [5]Organización Estados Iberoamericanos para la Educación, la Ciencia y la Cultura (OEI), Santo Domingo, Dominican Republic, [6]Universidad de Chile, Santiago, Chile, [7]Developmental Disorder Program, Mackenzie Presbyterian University, São Paulo, Brazil, [8]A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA, United States

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EDITED BY
Lawrence Fung,
Stanford University,
United States

REVIEWED BY
Debbie Spain,
King's College London,
United Kingdom
Paulina Buffle,
University of Geneva,
Switzerland

*CORRESPONDENCE
María Cecilia Montenegro
✉ maria.montenegro01@utrgv.edu

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Background: The COVID-19 pandemic brought an increased incidence of disease and mortality in the world at large, making it a particularly salient and stressful life event. For those individuals residing in Latin America, the pandemic was met with fragmented healthcare systems, economic downturn, and sociopolitical crisis which puts autistic individuals at risk for more detrimental outcomes. Behavioral and emotional challenges experienced by autistic individuals at the beginning of the pandemic could later develop into more severe symptomatology as the pandemic progresses. The present study aimed to explore changes in dysregulated (overt and internalizing) behaviors and preoccupation with getting sick during the COVID-19 pandemic among autistic children in 7 Latin American countries.

Method: Sample consisted of 1,743 caregivers, residing in: Argentina (n=677, 38.8%) Brazil (n = 156, 9%), Chile (n = 251, 14.4%), Dominican Republic (n=171, 9.8%), Mexico (n = 126, 7.2%), Uruguay (n = 259, 14.9%) and Venezuela (n=103, 5.9%). The majority of caregivers who completed the questionnaire were mothers (85.1%), and most had a male autistic child (81.6%). A series of independent sample t-tests were conducted to assess country differences in dysregulated behaviors and preoccupation with getting sick. Linear regressions were conducted to identify which demographic characteristics and micro-level contextual factors predicted dysregulated overt behaviors and psychological changes.

Results: Contextual factors, such as country of residence, were related to preoccupation with getting sick and dysregulated behavior. Particularly, residing in Mexico and Brazil were related to changes in preoccupation with getting sick and mental health concerns. Coexistence predicted dysregulated internalizing behaviors, while being older significantly predicted preoccupation with getting sick. Increased screen time only predicted anxiety.

Conclusion: Our findings highlight differences and predictions of behavioral challenges and psychological changes based on certain contextual factors and individual characteristics while experiencing severe life stressors such as a worldwide pandemic. This knowledge could help inform policies and decrees aimed at protecting those most vulnerable due to their increased difficulty adapting to change.

KEYWORDS

autism spectrum disorder, COVID-19, dysregulated behaviors, age, gender, coexistence

Introduction

In 2020, the world drastically changed as a result of the COVID-19 pandemic (1). Latin America (LATAM) was particularly impacted by the pandemic with one-third of all COVID-19 cases in the world and 34% of COVID-19 related deaths at the start of the pandemic (2, 3). This rate is expected to be higher than reported since COVID-19 testing in LATAM was insufficient due to limited resources and poor capacity (4, 5).

The known high rate of COVID-19 cases and deaths was likely perpetuated by a large treatment gap, poor health infrastructure, economic inequality, and political instability (6–10). In LATAM, most countries have fewer hospital beds and health professionals *per capita* than countries in more developed regions and thus an increased difficulty in meeting an increased demand (9, 10). Also, due to the newly implemented containment measures, in which many healthcare services were transitioned to online platforms, health professionals were met with the added challenge of modifying service delivery to electronic modalities but limited resources to do so (6). Financially COVID-19 came at a time when the region's Gross Domestic Product (GDP) had been declining in a way not experienced since 1950 (10).

Sociodemographic factors such as infrastructure, financial and sociopolitical environment can modify the impact of the pandemic. Moreover, throughout the pandemic, existing social discontent translated to lower trust in their government's handling of the pandemic (11). In LATAM, this lack of trust, in addition to aid shortages and an inability to afford isolation, meant decreased desire to comply with containment measures and thus increased probability of getting sick and infecting loved one.

When assessing the impact of COVID-19 in terms of psychological distress, a study by Silverio-Murillo et al. identified increased anxiety, insomnia and stress-related Google searches at the time when countries began employing stay-at-home orders (12). These results were further supported by a systematic review by Zhang et al., which assessed the prevalence of mental health symptoms in LATAM (13). Their findings showed high rates of depression and anxiety, yet it observed higher insomnia prevalence compared to Europe and Asia. This result could be due to poorly executed safety protocols and non-inclusive policies implemented after the pandemic (14, 15), thus increasing distress, particularly among historically vulnerable populations, such as autistic individuals in LATAM countries (16, 17).

COVID-19 and autism spectrum disorder

About one in every hundred children is diagnosed with autism spectrum disorder worldwide (ASD; (18)). In Latin America, prevalence rate is difficult to estipulate due to the limited number of epidemiological studies available (19). Of the few countries with known prevalence rates, numbers range from 17 to 52.6 in every in every 10, 000 individuals in Venezuela and Argentina, respectively, (20, 21). ASD is characterized by difficulties with social communication, repetitive behavior patterns, and focused interests (22). Also, some autistic individuals might experience difficulties shifting focus making it more challenging to distract themselves from a stressful life event (8). This impairment in cognitive flexibility is problematic when we consider that shifting one's perspective could help in the recovery process (8). Additionally, autistic individuals typically adhere to strict routines, and the disruption of these routines can be met with high levels of distress (23). Because of these characteristics, it is possible that autistic individuals perceive stressful life events more distressing or traumatic than non-autistic individuals (24). In the context of COVID-19 in which routines changed quickly (e.g., interruption of face-to-face schooling and therapeutic services and limitation of leisure activities), autistic individuals might have experienced it as a significant disruption to their lives (25) which could explain reports of increased fear, uncertainty, psychological distress, and psychosomatic difficulties at the start of the pandemic (25, 26).

Contextual micro and macro factors

The present study focuses on the influence of particular micro and macro environmental factors on dysregulated behaviors and psychological differences among autistic individuals throughout the start of the pandemic in LATAM (27, 28). At the micro-level, research indicates that household overcrowding predicted COVID-19 infection rates and mortality (29, 30). Furthermore, household overcrowding has been associated with worsening of behavioral problems in children (31). Moreover, housing quality and overcrowding can negatively impact household dynamics, family wellbeing, and overall health outcomes (32). Poor housing conditions and overcrowding can further complicate the increased need for isolation and quarantine to mitigate the surge of COVID-19 cases (33). The pandemic also shed light on other contextual issues. Due to limited social outings, individuals screen time usage increased, thus, negatively impacting overall emotional and physical health (34–37). This increase could be particularly taxing, considering that previous literature shows that increased screen time was related to increased irritability, concentration difficulties, mood disturbances, anxiety, and sleep dysregulation (36). This is especially relevant in the case of autistic individuals given the already high prevalence of co-occurring sleeping problems (38, 39).

At the macro level, COVID-19 related deaths and healthcare infrastructure could play a role in the functioning of autistic individuals. Research has indicated that in those countries harder hit by the pandemic there was an increase in mental health conditions (40). In LATAM autistic individuals faced particular circumstances as the increased rate of severe COVID-19 meant an increased demand for healthcare infrastructure that was already fraught in most countries (16, 41). Argentina, a country in our sample, had the largest number of available hospital beds per 1,000 individuals in LATAM (42); however, there were fewer than in other higher-income countries (e.g., Japan) (43). Before the pandemic started, the WHO used an overall efficiency index (OEI) to measure health system performance. This composite index assesses the efficiency of health systems in meeting specific goals, such as responsiveness (e.g., distribution), adequate financing, and inequality (44). According to the WHO, Chile has the highest OEI in Latin America, whereas Brazil scores almost half of it (45). However, Chile's healthcare expenditure falls well behind other countries with similar OEI such as Australia and Canada exposing some of the healthcare challenges in the region (44, 45).

Dysregulated behaviors and preoccupation with getting sick

Bauminger et al. described a cluster of ASD behaviors that predict social difficulties and peer unacceptance (46). These behaviors can be divided into two categories, dysregulated overt (externalizing) and internalizing behaviors. According to this classification, dysregulated overt behaviors include aggression, impulsivity, and impulse-control problems, while dysregulated internalizing behaviors include social withdrawal, anxiety, and mood issues (46). Past research has shown that the phenotypic expression of these dysregulated behaviors might vary depending on the gender of the autistic person, with females being more likely to experience internalizing behaviors, whereas males are more likely to exhibit overt behaviors (47, 48).

Life stressors, contextual factors, and individual characteristics can intensify dysregulated behaviors among autistic individuals (49–52). Given the significant changes and disruptions as a result of the COVID-19 outbreak, the pandemic has heightened levels of distress in autistic individuals, potentially leading to behavioral and emotional disturbances, as well as emotional duress (51, 53). Although multiple studies have explored the pandemic's impact on autistic individuals, most of these have been conducted in developed and high-income countries in Europe and North America. Amorim et al. compared behavioral changes in neurotypical and autistic children during the COVID-19 pandemic in Portugal (49). Their findings suggested that autistic individuals experienced behavioral changes (e.g., irritability, obsessiveness, hostility, impulsivity) and increased anxiety when compared to their neurotypical peers. Also, more than half of the autistic individuals in their sample experienced difficulties with emotional regulation (49). Furthermore, caregivers of autistic individuals identified social isolation, limited opportunity for outdoor activities, boredom, and increased online activity as the most problematic challenges experienced by their children during the pandemic (49).

Given the dearth of information regarding the impact of COVID-19 in autistic individuals in LATAM, the present study had three aims. First, this study sought to understand micro and macro contextual influences (e.g., household overcrowding and screen time) on behavioral and psychological changes in autistic individuals, as perceived by their caregivers, in LATAM as a result of COVID-19. Specifically, the study assessed differences in preoccupation with getting sick and overt and internalizing behaviors of autistic individuals, depending on their country of residence, COVID-19 related deaths, hospital beds per 1,000 individuals, and OEI. Second, the study examined micro-level contextual factors as predictors of dysregulated behaviors among autistic individuals as perceived by their caregivers. Lastly, the study assessed autistic individuals' demographics (e.g., age and gender) and their relationship to preoccupation with getting sick and overt and internalizing behaviors.

Methods

Sample

The sample consisted of 1,743 caregivers residing in 7 LATAM: Argentina ($n = 677$, 38.8%), Brazil ($n = 156$, 9%), Chile ($n = 251$, 14.4%), Dominican Republic ($n = 171$, 9.8%), Mexico ($n = 126$, 7.2%), Uruguay ($n = 259$, 14.9%), and Venezuela ($n = 103$, 5.9%). Data collection occurred from May 2020 to August 2020. The majority of participants were female (85.1%) and had a male autistic child (81.6%, see Table 1). To be included in the study, caregivers needed to be least 18 years old and have an autistic child, and be a resident of the included LATAM countries at the time of the study. Recruitment occurred through community support groups for caregivers with autistic youth, service agencies, physicians' offices, social media groups, and word of mouth.

Procedure

The present study is part of a larger research project conceptualized by a group of researchers and professionals who in 2015 formed an alliance called the *Red Espectro Autista Latinoamérica* (REAL) to help deepen the understanding of ASD in Latin America. These researchers developed this network as a response to a call made by previous publications to fill the ASD knowledge gap in other parts of the world outside the United States and Europe (7, 54). At the pandemic's start, REAL clinicians and researchers observed many rapid changes (e.g., lockdown, changes in service modalities, safety measures (6) and were interested in understanding the experience of autistic individuals and their families).

For this study, participants completed an online survey (google forms), which inquired about different aspects of the autistic individual sociodemographic characteristics, as well as service utilization in each of the included countries. Recruitment was conducted through community support groups, service agencies, pediatrician offices, word of mouth, and social media groups. Study procedures were approved by the Institutional Review Board (IRB) of The University of Texas Rio Grande Valley and the ethics boards of the different agencies with which the other national coordinators were affiliated. Data collection occurred from May 2020 until August 2020. Data was filled out in excel files in each country and merged in SPSS by one of the main researchers and two of her research assistants.

TABLE 1 Demographic characteristics of the sample ($N = 1{,}743$).

	N	%
Country		
Argentina	677	(38.8)
Brazil	156	(9.0)
Chile	251	(14.4)
Dominican Republic	171	(9.8)
Mexico	126	(7.2)
Uruguay	259	(14.9)
Venezuela	103	(5.9)
Type of Caregiver		
Father	171	(9.8)
Mother	1,484	(85.1)
Grandparent	23	(1.3)
Other	65	(3.8)
Diagnosis of Child		
Autism	295	(17.5)
Asperger	240	(14.3)
Pervasive Developmental Disorder (PDD)	144	(8.5)
PDD-Not Otherwise Specified	135	(8.0)
ASD	870	(51.7)
Gender of Child		
Male	1,423	(81.6)
Female	320	(18.4)
Age of Autistic Child		
0–6 years old	622	(35.7)
7–12 years old	673	(38.6)
13–18 years old	294	(16.9)
19+ years old	154	(8.8)

Instrument

The REAL network developed an online survey to inquire about the impact of the COVID-19 pandemic on autistic individuals in LATAM. Due to the novelty of the COVID-19 pandemic and the lack of instruments with psychometric properties normed with the population included in this study, a new instrument was developed by professionals (e.g., psychiatrists, psychologists, doctoral students, and researchers) from the countries included. The development of this survey was comprised of six stages: (1) meetings among professionals from each LATAM country to discuss needs being observed in autistic individuals; (2) drafting of questions to be included in the survey; (3) consensus for relevance and appropriateness of each item; (4) pilot testing to select the final items, and (6) pilot testing the final draft of the survey to assess its acceptability and relevance among families. The instrument was designed in Spanish and pilot tested to ensure its appropriateness for cross-cultural use. The principal researcher from Brazil and a Ph.D. student translated the questionnaire to Portuguese for the Brazilian sample. Throughout a series of meetings, agreement of the translated instrument was achieved. This translated document was also pilot tested with two mothers of autistic individuals to ensure questions were understandable, relevant, and non-stigmatizing.

Statistical analyses

For exploring countries' differences in preoccupation with getting sick and dysregulated behaviors of autistic individuals depending on country's infrastructure, health services efficiency and COVID-19 related deaths, independent sample *t*-tests were conducted (Tables 2, 3). Before the analyses were conducted, assumption of normality was assessed and range of skewness ($SE < 3$) and kurtosis (<10) were utilized (57). Both preoccupation with getting sick and dysregulated behaviors were normally distributed. For homogeneity of variance, the assumption was met as assessed with F_{max} with a maximum value of 10 accepted (58).

TABLE 2 COVID-19 cases and deaths, overall efficiency index, and medical capacity.

	COVID-19-cases adjusted by population (%)	COVID-19-deaths adjusted by COVID cases (%)	Hospital Beds per 1,000	Overall Efficiency Index
Country				
Brazil	9.8	2.8	2.1	0.57
Argentina	11.4	2.2	5.0	0.72
Uruguay	11	1.6	2.4	0.75
Mexico	2.6	7.7	1.0	0.76
Venezuela	1.2	1.2	0.9	0.78
Dominican Republic	3.2	1.1	1.6	0.79
Chile	8.5	2.3	2.1	0.87

Data from The World Bank (55) for Hospital beds per 1,000, World Health Organization (56) for COVID-19 cases and COVID-19 deaths, and World Health Organization (45) for Overall Efficiency Index.

TABLE 3 Differences in dysregulated internalizing behaviors and preoccupation with getting sick by country.

Country Comparisons	Dysregulated internalizing behaviors			Preoccupation with getting sick		
	M	SD	*t*	M	SD	*t*
COVID-19 Deaths			3.34*			2.13*
Mexico	6.99	1.61		3.19	0.99	
Dominican Republic	6.31	1.79		2.92	1.12	
Overall Efficiency Index			3.32*			3.49*
Chile	7.065	1.74		3.08	1.09	
Brazil	7.63	1.52		3.44	0.85	
Hospital Beds			0.37			0.45
Argentina	7.20	1.58		3.18	0.74	
Venezuela	7.26	1.72		3.15	0.87	

*$p < 0.05$, **$p < 0.01$, and ***$p < 0.001$.

TABLE 4 Linear regression analysis for crowded conditions predicting dysregulated overt behaviors.

	B	SE	β	*T*	95% CI
Crowded condition	9.72	0.27		36.27	9.19–10.24***
Coexistence					
Worst	1.92	0.11	0.30	17.32	1.71–2.14***
People in household					
More than 3	−0.14	0.19	−0.02	−0.72	−0.53–0.25
House size					
More than 50 m^2	−0.12	0.12	−0.02	−1.04	−0.36–0.11
Outside space					
No	0.17	0.13	0.03	1.32	−0.08–0.43

$R^2 = 15.2\%$. $p < 0.05$, **$p < 0.01$, and ***$p < 0.001$.

TABLE 5 Linear regression analysis for prediction of anxiety, mood, and sleep dysregulation based on screentime increase.

	Anxiety			Mood			Sleep dysregulation		
	B	β	95% CI	B	β	95% CI	B	β	95% CI
Increased screentime	0.121	0.06	0.02–0.23*	0.09	0.04	−0.01–0.19	0.00	0.05	−0.10–0.10

$R^2 = 0.03\%$ for anxiety regression model, $R^2 = 0.00$ for sleep dysregulation regression model, and $R^2 = 0.02$ for mood regression model. *$p < 0.05$, **$p < 0.01$, and ***$p < 0.001$.

TABLE 6 Linear regression analysis for gender of autistic child as predictor of dysregulated behaviors.

	Dysregulated internalizing behaviors					Dysregulated overt behaviors				
	B	β	*t*	Sig. (*p*)	95% CI	B	β	*t*	Sig. (*p*)	95% CI
Gender	0.01	0.002	0.10	0.92	−0.19–0.21	0.05	0.01	0.35	0.72	−0.23–0.34

The rest of the study's aims were tested by five linear regression analyses conducted separately. These attempted to (1) predict dysregulated overt behavior among those who reside in more crowded conditions (more habitants living in the same household, fewer squared meters, and no yard) and those who reported worsening coexistence (Table 4); (2) predict anxiety, preoccupation with getting sick, and mood among those who increased screen time use (Table 5); (3) predict dysregulated overt and internalizing externalizing behaviors among different gender (Table 6); and (4) predict if older autistic individuals experienced increased preoccupation with getting sick (Table 7). To test assumptions before conducting these linear regressions, independence of residuals were assessed by the Durbin-Watson statistic, and only values between one and three were accepted (59). To ensure linear relationship with dependent variables, independent variables were dummy coded (58). Finally, homogeneity of variances was assessed with F_{max} ratio. All statistical analyses were conducted using IBM SPSS, version 26.

TABLE 7 Linear regression analysis for age of autistic child as predictor of preoccupation with getting sick.

	B	β	t	95% CI
Age Group	3.13		129.11	3.09–3.18***
13 and older	0.16	0.08	3.27	0.06–0.25*

$R^2 = 0.6\%$. $^*p < 0.05$, $^{**}p < 0.01$, and $^{***}p < 0.001$.

Variables

Autistic individuals' characteristics

Caregivers were asked about the age and gender of their child. Response options for age included: 0–6 years old, 7–12 years old, 13–18 years old, and 19 years old and older. For analyses, age was transformed into a binary variable (0 = younger than 12 years of age, 1 = 13 years of age and older) to make comparisons between children and adolescents and young adults. For gender, participants were given three options: female, male, and other.

Contextual factors

Caregivers were asked to indicate their country of residence, number of people living in the house (i.e., 2, 3–5, 5+ people living in the household), squared meters of their home, whether they had outside space (e.g., a yard), family coexistence (1-*Much worse than before* to 5-*Much better than before*) and screen time usage (1-*Increased a lot* to 5-*Decreased a lot*). Number of people living in the house was collapsed into a binary variable to better compare crowding (0 = 2 people living in the house, 1 = 3 and more people living in the house). For housing, a house below 50 m^2 is considered extremely small and characteristic of crowded housing for a family of any size (60, 61), and thus housing size was collapsed into a binary variable (0 = Less than 50 m^2, 1 = More than 50 m^2). Lastly, for the comparison of screen time usage, this variable was collapsed into a binary one (0 = No Increased Screen Time, 1 = Increased Screen time). Included in the "No Increased Screen Time" were those that reported a decrease or no change in screen time usage. In the "Increased Screen Time" category, those that reported an increase by "a little" or "a lot" were included. Of the total sample, 80.2% of caregivers reported an increased screen time usage in their children and 19.8% reported no increased screen time.

Country differences

Three factors were assessed to predict increased preoccupation with getting sick and dysregulated internalizing behaviors among autistic individuals as reported by their caregivers. First, number of COVID-19 related deaths was used as proxy to assess country's COVID-19 burden (62, 63). Number of hospital beds per 1,000 people was used as a proxy to evaluate countries' health infrastructure and resources (55, 64). Lastly, to address overall infrastructure and healthcare system capacity, each country's OEI was examined (44, 45). Countries with opposing values on the listed factors were compared. In terms of COVID-19 related deaths, Mexico had the most fatalities (7.7%) and the Dominican Republic the least (1.1). When considering infrastructure, Venezuela had the lowest hospital beds per 1,000 people (0.9), whereas Argentina had the most (5). Finally, Brazil had the lowest OEI (0.57), while Chile had the highest (0.87). These countries were compared against each other based on the respective factor of interest (Venezuela against Uruguay, Mexico against the Dominican Republic, and Brazil against Chile).

Dysregulated behaviors

The dependent variables consisted of a series of questions asking about behavioral changes experienced by the autistic individual as perceived by their caregiver. Participants responded to these items using a Likert scale, from 1-*Much less than before* to 5-*Much more than before*. An example included: "The person with ASD has been hitting, pinching, biting, or pushing others." To align with previous literature (46), dysregulated overt behaviors included three items pertaining to irritability, aggression, and concentration; while internalizing behaviors included two items that inquired about changes in anxiety and mood. For dysregulated overt behaviors, Kendall's tau-*b* correlation there were strong positive associations between concentration difficulty and irritability $\tau b = 0.322$, $p < 0.001$, concentration difficulty and aggression $\tau b = 0.219$, $p < 0.001$, and aggression and irritability $\tau b = 0.477$, $p < 0.001$. Correlation analysis for internalizing behaviors indicated a strong, positive association between anxiety and mood $\tau b = 0.534$, $p < 0.001$.

Preoccupation with getting sick

Caregivers were asked about their child's preoccupation with getting sick ("The person with ASD has shown an increased preoccupation with getting sick"). Responses were on a 5-point Likert scale and ranged from "Much less than before" to "Much more than before."

Results

Country differences by hospital beds, COVID-19 deaths, and OEI

Our first hypothesis was supported. Results indicated statistically significant differences in preoccupation with getting sick and dysregulated behaviors between Mexico, the country with the highest COVID-19 mortality rate, and the Dominican Republic, the country with the lowest mortality rate (Table 3). Compared to the Dominican Republic, Mexico had significantly higher dysregulated internalizing behaviors, $t(292) = 3.34$, $p = 0.001$, $d = 0.68$, and preoccupation with getting sick, $t(295) = 2.13$, $p = 0.034$, $d = 0.27$.

Furthermore, it was expected that autistic individuals residing in Venezuela, the country with the lowest hospital beds *per capita*, would experience increased preoccupation with getting sick and dysregulated internalizing behaviors when compared to Argentina, the country with the highest hospital beds. Results suggested there were no statistically significant differences between Venezuela and Argentina in terms of dysregulated behaviors ($p > 0.05$) nor in preoccupation with getting sick ($p > 0.05$).

It was also hypothesized that those residing in Brazil, the country with the lowest OEI, would show a greater preoccupation with getting sick and increased dysregulated internalizing behaviors than autistic individuals living in Chile, which had the highest OEI. Compared to Chile, Brazil had significantly higher dysregulated internalizing behaviors, $t(399) = 3.20$, $p = 0.001$, $d = 0.56$, and preoccupation with getting sick, $t(405) = 3.49$, $p = 0.001$, $d = 0.36$.

Crowded conditions and dysregulated overt behaviors

To determine if contextual factors predicted dysregulated overt behaviors, a linear regression was conducted. Results (see Table 4) indicated that the model explained 15% ($R^2 = 0.15$) of the variance and that it was significant, $F(4, 1{,}702) = 76.22$, $p < 0.01$. It was found that worst coexistence significantly predicted dysregulated overt behaviors ($\beta = 1.9$, $p < 0.001$).

Screen time use and psychological concerns

A second linear regression was conducted to determine if increased screen time predicted worsening of sleep patterns, increased anxiety, and worsening of mood. Screen time changes did not significantly predict increased dysregulation in sleep patterns, $F(1, 1{,}726) = 0.00$, $p > 0.05$, or in mood, $F(1, 1{,}701) = 3.17$, $p > 0.05$, but it significantly predicted increased anxiety, ($F(1, 1{,}706) = 5.17$, $p < 0.001$, $R^2 = 0.003$; $\beta = 0.05$, Table 5).

Autistic individuals characteristics

Gender and dysregulated overt and internalizing behaviors

The third and fourth linear regressions conducted attempted to predict differences in dysregulated overt and internalizing behaviors between both genders of autistic individuals whose caregivers participated in the study. Although it was expected that males would exhibit more overt behaviors and females would show increased internalizing behaviors, gender had no significant effect on dysregulated overt or internalizing behaviors ($p > 0.05$; Table 6).

Age and preoccupation with getting sick

Lastly, it was hypothesized that older autistic individuals would exhibit an increased preoccupation with getting sick. Results from a linear regression analysis suggested that age of the autistic individual significantly predicted preoccupation with getting sick, $F(1, 1{,}742) = 10.69$, $p = 0.001$, $R^2 = 0.006$, with older age significantly predicting preoccupation with getting sick ($\beta = 0.05$, $p = 0.001$; Table 7).

Discussion

It was expected that autistic individuals residing in the country showing highest COVID-19 related deaths (Mexico) would exhibit a greater preoccupation with getting sick and dysregulated internalizing behaviors than those residing in the country with the lowest mortality rate (Dominican Republic). Consistent with our hypothesis, our results indicated that autistic individuals in Mexico experienced increased dysregulated internalizing behaviors which could be explained by the toll of Mexico's high COVID-19 mortality rate. A systematic review by Santomauro et al. reported increased depressive and anxiety disorders in those countries hit harder by the pandemic, and thus increasing the disability adjusted life years (DALYs) a measure for health years lost due to mortality or disability (40). A study by Sideropoulos et al., which included a cross-country perspective concerning anxiety among those with neurodevelopmental concerns and their family members during COVID-19, also reported increased internalizing concerns, particularly anxiety, during the COVID-19 pandemic. In said study, despite pre-existent anxiety of parents and their children being a predictor of increased anxiety during the pandemic, other factors were identified as influencing its increment. For example, both parents and children with neurodevelopmental concerns experienced increased anxiety during the start of the pandemic due to fears of getting sick. Still, as time passed, parents continued experiencing increased anxiety due to their children's limited opportunities for social contact as more safety measures were being established to decrease contagion (65). For children with neurodevelopmental concerns, those with medical concerns exhibited increased anxiety (65). These results align with results from the present study, which show the impact of the pandemic in terms of deaths predicted internalizing concerns in autistic children as reported by their parents. It is also possible that due to the increased mortality rate, parents prevented social contact, which exacerbated the overall household anxiety due to limited social contact and outside support being received. Autistic individuals residing in Mexico also experienced increased preoccupation with getting sick. It is important to consider possible factors influencing these differences, such as a country's size and other economic measures. The Dominican Republic has a population of approximately 11 million people and an area of 48,311 km^2, making it a significantly smaller country than Mexico, which has a population of roughly 128 million individuals and a size of 1.964.375 km^2. It could be inferred that containment measures were easier to implement in the Dominican Republic, which was able to manage the spread of COVID-19 during the first few months of the pandemic by controlling movement into the country, implementing curfews and mobility restrictions, limiting gatherings, and closing public services which lowered the risk of illness (66–70). Also, in the Dominican Republic, there were subsidies to assist those employees that had their jobs suspended due to the pandemic and economic assistance to those with informal jobs, students, and those most vulnerable to the COVID-19 virus (71–73). These measures further helped ease the burden of COVID-19.

Due to the severity of the pandemic in terms increased burden on health systems (74), the present study assessed infrastructural differences between the two countries that showed stark differences in terms of hospital beds *per capita* (Argentina and Venezuela). Results yielded no statistical differences in preoccupation with getting sick or dysregulated internalizing behaviors between these two countries. These results should be interpreted with caution due to lack of transparency of public health data in Venezuela. Reports have emerged suggesting a much larger pandemic impact than what has been officially documented, suggesting higher infection rates and COVID-19 related deaths (75). Thus, it is possible that individuals in Venezuela were not adequately informed of the actual impact of the pandemic, and as such, decreasing autistic individuals' concerns. Another possible explanation is the ongoing economic and sociopolitical crisis being experienced in Venezuela in terms of food shortages, poor economy, fragmented infrastructure (e.g., water and power outages) and limited amount of service providers which, due to their immediate severity, could take the lead in terms of focus of preoccupation and concern (76). In addition, this is not the first infectious disease experienced by the country. Outbreaks of preventable infectious diseases such as measles, malaria, and diphtheria have been an issue in Venezuela in the recent past (75). For this reason, it is possible that those residing in Venezuela, who already experience high levels of psychological distress, could have developed distress tolerance (77). Previous research has shown that despite an association between trauma and adverse mental health, those with high levels of distress tolerance experience less adverse mental health outcomes (78).

When contemplating the OEI, a comparison was made between Brazil, which had the lowest health index, and Chile with the highest index in our sample. The analysis showed statistically significant differences in preoccupation with getting sick and dysregulated internalizing behaviors, with these two being higher in Brazil. To understand these results, it is important to consider the impact of COVID-19 in the local context. Brazil had the first confirmed case of COVID-19 in LATAM by February 2020, while Chile did not get a case until March (79). COVID-19 cases quickly increased in Brazil, making it the third-largest country in the world in terms of infection rate (74) and second in deaths, with over 490 thousand (56). The high and quick rates of infection were also met with a poor national response plan (74). For example, websites that provided public data offered by Brazil's Health Ministry were taken down, limiting information available to the public concerning the epidemiological status of COVID-19 (80). Additionally, Brazil's federal government downplayed the severity of the pandemic and discouraged the use of safety protocols (74). Furthermore, the rapid increase of severe COVID-19 cases was met with health systems that quickly collapsed, resulting in high death rates (74). Therefore, it is not surprising that Brazilian participants in this study endorsed increased preoccupation with getting sick and dysregulated internalizing behaviors since the COVID-19 pandemic started. When we observe Chile, not only were overall health systems more efficient, but measures that prepared the country to better handle the pandemic were already in place. For instance, in 2018 Chile had already established a disaster management model, which utilized the knowledge gained from Chile's previous experiences with natural disasters and included guidelines to support healthcare workers, implementation of protocols, and monitoring of systems for mental health practitioners (79). It is important to note that despite the pandemic precipitating the use of other service delivery modalities in many parts of the world, such as Telehealth, which have shown promising results in treating challenging behaviors (81), in LATAM limited infrastructure and equipment proved difficult for the proper implementation of remote healthcare delivery (82). For example, in LATAM internet connection can be slower and technical support less readily available. In addition, LATAM countries might have strict regulations and policies that could impede the utilization of telehealth platforms, or the opposite; countries might lack regulations making service providers reticent to implement said services (82). Thus, it is unsurprising that in countries like Brazil where healthcare was already problematic before the pandemic, Telehealth was not readily available to help ameliorate the increasing challenging behaviors reported by caregivers.

To better understand changes at the micro-level, this study focused on crowded conditions. Housing size, number of family members residing in the household, having outside space, and family coexistence changes were explored as predictors of worsening of dysregulated overt behaviors. In this model, only the worsening of family coexistence significantly predicted changes in these behaviors. These results could be partially related to ASD core characteristics that make it difficult for autistic individuals to adapt when confronted with disruptions to their routines (83, 84). It is possible that factors such as housing size, outside space, and family members living in the house did not impact participants' routines, but changes in coexistence did. A systematic review by Yilmaz et al. indicated that anxiety and stress among caregivers increased during the pandemic (85). And thus, this study's results can help dispel autism misconceptions concerning autistic individuals lacking empathy or awareness of other people's emotions. Despite autistic individuals often being portrayed as "uncaring," previous research has shown that while some may have difficulties with cognitive empathy (e.g., understanding other people's perceptions), they do not have difficulties with emotional empathy (e.g., understanding and sharing others emotions (86)).

Our findings showed screen-time did not predict worsening of sleep patterns, which is inconsistent with previous literature. Associations have been identified between excessive screen time and shorter sleep time among young children, proposing that the light from screens influences melatonin levels, circadian rhythms, and rapid eye movement sleep (87). Yet, for autistic individuals, sleep issues are already a common problem, with 50–86% experiencing sleep issues pre-pandemic (38, 39). The lack of significant results about sleep in our study could be attributable to pre- existing sleep difficulties. If autistic individuals in our sample already had sleep issues, a bedtime routine might have already been in place (88), and thus screen time usage would have not disrupted sleeping patterns. However, increased screen time significantly predicted a slight increase in anxiety in our sample, which is consistent with previous literature showing an association between screen time and anxiety (89). More time spent on electronics, combined with lockdowns, social distance protocols, and changes in treatment modalities could have significantly impacted autistic individuals, and thus explain the increased anxiety levels.

In addition, our findings indicated that dysregulated behaviors were not predicted by gender. Autism research has offered mixed results when comparing internalizing (e.g., anxiety, mood) and externalizing (e.g., aggression) behaviors among genders. For instance, Margari et al. found no statistical differences among both genders in dysregulated behaviors (90). These results seem inconsistent with other literature indicating that females are more likely to experience internalizing behaviors, whereas males are more likely to exhibit externalizing ones (48). In the present sample, one can deduce that decreased social interactions due to containment protocols and reduced social expectations leveled the field in terms of dysregulated behaviors. It is possible that strategies employed by autistic individuals (learned or developed) to hide autistic characteristics for social acceptance (91, 92), decreased during the pandemic due to increased isolation and limited outside contact, accounting for no gender differences in dysregulated internalizing behaviors.

Lastly, it was hypothesized that older autistic individuals (teenagers and adults) would exhibit a greater preoccupation with getting sick. In our sample, as expected, both older individuals showed greater preoccupation than younger children. A recent study by Schott et al. showed that older autistic individuals were at greater risk of COVID-19 exposure due to having been hospitalized more often than neurotypical individuals and to be more likely to either live in a care facility or receive services in the home (93). Therefore, it is imperative to make older individuals a priority in terms of prevention measures by healthcare and service providers (e.g., mask-wearing, hand washing, etc.) and when planning health treatments (e.g., vaccines) (94).

This study has some limitations. First, it lacked longitudinal data that captured individuals' experiences at different times of the pandemic. Another limitation is the limited information on autism prevalence rates in the region limited generalization. However, the current sample size allowed for a robust statistical power according to our statistical analyses. A third limitation is the lack of a confirmed autism diagnoses by a specialist, since data collected solely consisted of caregiver reports. However, it is worth noting that this does not steer away from the focus of the study, which is to understand caregivers' perceptions and autistic individuals' changes when navigating the start of the COVID-19 pandemic. Fourthly, caregivers required internet access to complete the online survey utilized for the present study. Thus, individuals with limited internet accessibility were not included, limiting the representation of the sample. Lastly, some results showed only small effect sizes. This may be due to the quickly changing and complicated nature of the COVID-19 pandemic (e.g., lockdowns, mask mandates, social distancing, development of vaccinations, etc.), as the influence of variables of interest and others not assessed could show stronger effects at different points in time. Additionally, analyses conducted did not control for intellectual ability, language deficits, and symptom severity of autistic individuals, and thus their influence on the different variables of interest could not be determined.

In summary, the COVID-19 pandemic was an acute stressor that was experienced differently in LATAM according to country of residence, age of the autistic individual and family coexistence. Taken all results together, older autistic individuals residing in Brazil and Mexico fared worse than others in terms of preoccupation with getting sick and dysregulated internalizing behaviors. Previous literature has indicated that when compared to caregivers in other LATAM countries, Brazilian caregivers are more likely to report service barriers, lack of information, frustrations when attempting to access services, and overall helplessness when caring for their autistic child (95). It is possible that these barriers to proper care only worsened during the pandemic, increasing autistic individuals' preoccupation with getting sick and internalizing behaviors. For those residing in Mexico, the pandemic meant a challenging environment due to not only large rates of mortality, but also because of precarious healthcare systems and shortages of safety and preventive equipment (96, 97).

This project has sociopolitical, clinical, and research implications. Some of the most salient findings of this project point towards a need to further investigate countries' handling of large environmental changes in terms of policies and safety measures, and their impact on autistic individuals. For example, despite our hypothesis expecting countries with better overall health services and infrastructure, such as Chile, to endorse fewer internalizing issues, caregivers reported increases. More research is needed to assess sociopolitical aspects of the pandemic, especially if implemented policies failed to better meet the needs of autistic individuals and their families. Additionally, despite the absence of gender differences in terms of predicting dysregulated behaviors, societal expectations and their impact on dysregulated behaviors when confronted with life stressors need to be further explored, particularly in relation to parental attitudes and expectations. Finally, when exploring contextual factors such as housing size, number of people living in the house, and outdoor space, only worsening of coexistence predicted internalizing behaviors in autistic children. This knowledge can help conceptualize treatments needed in times of unexpected life stressors among autistic individuals to ensure parental stress and coexistence issues do not prove detrimental to their emotional and psychological wellbeing.

Data availability statement

The original contributions presented in the study are included in the article/supplementary materials, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by University of Texas Rio Grande Valley. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

MM: Conceptualization, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. AR: Writing – review & editing. JH: Writing – review & editing. BV: Writing – review & editing. GG: Data curation, Supervision, Writing – review & editing. CA: Data curation, Writing – review & editing. DV: Conceptualization, Data curation, Writing – review & editing. NB: Writing – review & editing. SC: Writing – review & editing. ARa: Writing – review & editing. ARo: Writing – review & editing. RG: Writing – review & editing. CP: Data curation, Writing – review & editing. GL: Writing – review & editing. CM-N: Data curation, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Cecilia Montiel Nava,
The University of Texas Rio Grande Valley,
United States

REVIEWED BY
Arianna Bentenuto,
University of Trento, Italy

*CORRESPONDENCE
Roberta Minutoli
✉ Roberta.minutoli@irib.cnr.it

†These authors have contributed equally to this work

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From crisis to opportunity: integrating insights from COVID-19 into the autism research

Chiara Failla[1,2†], Paola Chilà[1,3†], Noemi Vetrano[1,4], Germana Doria[1,3], Ileana Scarcella[1,3], Roberta Minutoli[1,3*], Stefania Gismondo[1], Giovanni Pioggia[1†] and Flavia Marino[1†]

[1]Institute for Biomedical Research and Innovation (IRIB), National Research Council of Italy (CNR), Messina, Italy, [2]Classical Linguistic Studies and Education Department, Kore University of Enna, Enna, Italy, [3]Faculty of Psychology, International Telematic University Uninettuno, Roma, Italy, [4]Department of Cognitive, Psychological Science and Cultural Studies, University of Messina, Messina, Italy

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Introduction

The pandemic COVID-19 pandemic has presented substantial obstacles to families around the world. Several countries have implemented preventative measures, leading notable disturbance in daily routine. Lockdowns, which have limited physical attendance at school, required parents to adapt to remote working and strongly discouraged social interactions, have radically altered the family landscape. Research indicates that the pandemic has the potential to elicit greater psychological distress in children with neurodevelopmental disorder, like autism spectrum disorders (ASD) (1). The concept of vulnerability, acknowledged by the World Health Organization, plays a crucial role in the context of people with ASD (2). The distinctive difficulties in communication, socialization and executive functions associated with ASD have made this segment of the population more fragile during the pandemic (3). Consequently, these children thrive in highly structured environments and unexpected changed can induce stress, anxiety, or confusion, as noted by Baron-Cohen (4).

Preventive measures implemented during the last global health crisis, have exerted an influence on the well-being of ASD population. This impact is further accentuated by the high incidence of concurrent mental health issues (5), disruptions to daily routines and reduced access to essential support systems. Some children with ASD have experienced a decline in stress levels as a result of fewer situation requiring social interactions and environmental demands potentially resulting in enhancements in their emotional and behavioral well-being (6, 7). A global initiative to transition health services to a "remote by default" model has been in place since March 2020 in response to the pandemic (8). Telemedicine has become a central focus, constantly to address new clinical demands through digital advancements.

Telehealth promotes the relationship between patients and doctors while alleviating pressure on healthcare systems (9). Technology-mediated care, including real-time video calls, health monitoring via medical devices, email, audio and instant messaging, virtually connects doctors with patients or caregivers, eliminating the need for physical proximity. This strategy has also been employed to provide assistance to ASD families.

Effect of healthcare service

As highlighted in their study conducted by Zerbo, individuals with ASD require higher levels of service utilization and incur greater costs compared to those with other disabilities (10). However, compelling evidence highlights substantial unmet healthcare needs existing even prior to the pandemic. Preceding the pandemic, people with ASD already experienced disruptions in the services they regularly used, attributed to factors such as staff turnover, shortages, mandated closures of community resources, and significantly altered or reduced access to essential specialized services (11). Telemedicine is effective and preferred by some patients in behavioral health services (12, 13). The benefits of telemedicine extend beyond mere convenience, particularly given the severe limitations on the availability and capacity of in-person care during the pandemic. Telemedicine emerges as a key element, reducing costs and improving geographic accessibility for patients, particularly for children with developmental disabilities, by involving healthcare workers and siblings (14).. Telehealth has become a vital resource, bridging the gap left by the constrained capabilities of providers and health systems. However, research in the scientific landscape on the sustainability of telemedicine for individuals with ASD presents a mixed picture (15). While young people with ASD and their parents generally perceive telemedicine positively, technical issues pose a concern in the delivery of these services (16). Despite these challenges, telemedicine proves to be a valuable solution in the field of autism.

Telehealth and autism

The utilization of telemedicine in the context of autism has proven to be particularly impactful, especially during the years of the pandemic. In the study by Narzisi 2020 (17), the importance of clear communication about COVID-19 to children, emphasizing structured routines and suggesting the use of games, such as Lego therapy, to improve social cognition in children with ASD and to propose rules for sharing video games and the Internet, reducing social isolation and encouraging shared activities based on common interests between parents and children. This method of intervention has demonstrated remarkable effectiveness in enhancing various skills in children with autism. The remote delivery of services, including individual therapy, family counseling, and support for skill development, has been instrumental in overcoming the challenges posed by in-person restrictions. The adaptability of telehealth has not only facilitated consistent access to necessary interventions but has also showcased its potential to effectively address the unique needs of individuals with autism, providing a valuable avenue for improvement in diverse aspects of their development (18). A review study conducted by Courtney L. et al. in 2023 (19) explored the use of telemedicine for interventions with individuals with ASD. These results indicate that telemedicine has led to positive outcomes, involving active engagement of parents in clinical intervention practices with their ASD children. Additionally, direct involvement of ASD children in on line therapy sessions has been associated with positive outcomes, emphasizing the potential benefits of telemedicine for both parents and children. Several studies have consistently demonstrated the validity of telemedicine in the context of autism, encompassing both direct interventions with children (20–22) and programs involving active parental engagement aimed at teaching skills to enhance their children's adaptive capabilities (23–25). The evidence underscores the effectiveness of telemedicine as a valuable and versatile tool for delivering targeted interventions, promoting skill development, and fostering adaptive behaviors in children with autism. This approach not only extends the reach of intervention strategies but also empowers parents to actively participate in their children's developmental journeys, highlighting the potential of telemedicine as a comprehensive and accessible avenue for supporting families of autistic children. Furthermore, looking to the future, as highlighted by Narzisi A., 2020 (26) telemedicine could be useful for quicker diagnoses of autism, overcoming long waiting lists and integrating with conventional methods to guarantee early diagnoses that have a positive impact on the development path of children with ASD, as the effectiveness of the use of this modality has also been demonstrated in the diagnostic field.

Discussion

During periods of emergency due to sudden disasters, individuals with disabilities experience significant challenges (27). Given the heightened vulnerability of individuals with ASD in such situations, it is essential to proactively work on preparing for these individuals who are more susceptible to managing emergency periods. Clinical services supporting individuals with ASD experienced a significant disruption due to the COVID-19 pandemic peak (28). To address this shortage of service, health systems promptly mobilized to compensate for the clinical support services that could be provided to the population. Telemedicine has provided the opportunity to fill the gap caused by suspension of in-person therapies that were impossible to conduct during the most acute phases of the pandemic. Ensuring continuity in support services can help individuals navigate the process of adapting to changes in their environment. Telemedicine is a valuable resource that needs to be expanded, accompanied by adequate dissemination of information about its usage (29). Interventions provided during the pandemic era have witnessed a high level of collaboration among families, caregivers and clinicians to facilitate better adaptation for individuals with ASD. A crucial aspect during this period has been addressing responses to anxiety and uncertainty stemming from a situation that disrupted every pre-established pattern of life (30). Likewise, individuals with ASD might endure signs of immediate stress or post-traumatic stress disorder (PTSD) beyond the active pandemic duration (31). Over the past decade, there has been the creation of training initiatives aimed at supporting community first responders in identifying and defusing situations involving distressed individuals with autism (32–34). For the future, it would be beneficial to develop plans and strategies in anxiety-free situations, to identify appropriate coping strategies for dealing with unexpected events. Learning such strategies in anxiety-free situation has been shown to facilitate the acquisition of these skills. An approach focused on finding valid alternative strategies could be a winning way to promote a sense of independence in individuals (35).

In conclusion, it is crucial to reflect on the main challenge faced by individuals with ASD during the pandemic, which is the adaptation to a new way of approaching daily life, breaking established patterns (36). Clinical operators have played a fundamental role in managing this global crisis, effectively providing support to a more vulnerable segment of the population and equipping them with the necessary tools to adapt better to everyday life. Healthcare professionals have a unique opportunity to cultivate fundamental skills in individuals with autism through everyday interactions, focusing on problem-solving, identifying alternative choices, and predicting outcomes. This sustained commitment during non-crisis moments is essential for building resilience and fostering confidence in managing uncertainty (37). Lessons learned from the pandemic underscore the importance of proactive intervention through telemedicine, providing vital support for the ongoing development of these essential skills in individuals with autism. Telehealth, when integrated into ongoing care strategies, not only addresses immediate challenges but also establishes the foundation for long-term resilience and adaptability in individuals with autism.

Author contributions

CF: Conceptualization, Writing – original draft, Writing – review & editing. PC: Writing – original draft, Writing – review & editing, Conceptualization. NV: Writing – original draft. GD: Writing – original draft. IS: Writing – original draft. SG: Project administration. RM: Supervision, Writing – review & editing. GP: Project administration, Supervision, Writing – review & editing. FM: Project administration, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Michaela DuBay,
University of Virginia, United States

REVIEWED BY
Cecilia Montiel Nava,
The University of Texas, United States
Maria Giuseppina Petruzzelli,
University of Bari Aldo Moro, Italy

*CORRESPONDENCE
Maureen S. Durkin
maureen.durkin@wisc.edu

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Economic impacts of the COVID-19 pandemic on families of children with autism and other developmental disabilities

Olivia M. Pokoski[1,2], Hayley Crain[2,3], Carolyn DiGuiseppi[4], Sarah M. Furnier[1,2], Eric J. Moody[5], Cy Nadler[6], Karen Pazol[7], Jessica Sanders[8], Lisa D. Wiggins[7] and Maureen S. Durkin[1,2,3]*

[1]Department of Population Health Sciences, University of Wisconsin-Madison, Madison, WI, United States, [2]Waisman Center, University of Wisconsin-Madison, Madison, WI, United States, [3]Department of Pediatrics, University of Wisconsin-Madison, Madison, WI, United States, [4]Department of Epidemiology, Colorado School of Public Health, University of Colorado, Aurora, CO, United States, [5]Wyoming Institute for Disabilities, University of Wyoming, Laramie, WY, United States, [6]Division of Developmental and Behavioral Health, Children's Mercy Kansas City, Kansas City, MO, United States, [7]National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA, United States, [8]Department of Pediatrics and Department of Neurology, University of Colorado School of Medicine, Aurora, CO, United States

Background: To control the spread of the coronavirus disease (COVID-19), many jurisdictions throughout the world enacted public health measures that had vast socio-economic implications. In emergency situations, families of children with developmental disabilities (DDs), including autism, may experience increased difficulty accessing therapies, economic hardship, and caregiver stress, with the potential to exacerbate autism symptoms. Yet, limited research exists on the economic impacts of the COVID-19 pandemic on families of children with autism or another DD compared to families of children from the general population.

Objectives: To assess impact of the COVID-19 pandemic related to parental employment and economic difficulties in families of children with autism, another DD, and in the general population, considering potential modification by socioeconomic disadvantage before the pandemic and levels of child behavioral and emotional problems.

Methods: The Study to Explore Early Development (SEED) is a multi-site, multi-phase, case-control study of young children with autism or another DD as compared to a population comparison group (POP). During January-July 2021, a COVID-19 Impact Assessment Questionnaire was sent to eligible participants (n=1,789) who had enrolled in SEED Phase 3 from September 2017-March 2020. Parents completed a questionnaire on impacts of the pandemic in 2020 and completed the Child Behavior Checklist (CBCL) to measure behavioral and emotional health of their child during this time. Multiple logistic regression models were built for employment reduction, increased remote work, difficulty paying bills, or fear of losing their home. Covariates include group status (autism, DD, POP), household income at enrollment, child's race and ethnicity, and binary CBCL Total Problems T-score (<60 vs. $\geq$60). Unadjusted and adjusted odds ratios (aOR) and 95% confidence intervals (CI) were calculated.

Results: The study included 274 children with autism, 368 children with another DD, and 385 POP children. The mean age of 6.1 years (standard deviation, 0.8) at the COVID-19 Impact Assessment did not differ between study groups. Parents of children with autism were less likely to transition to remote work (aOR [95% CI] = 0.6 [0.4, 1.0]) and more likely to report difficulty paying bills during the pandemic (1.8 [1.2, 2.9]) relative to parents of POP children. Lower income was associated with greater employment reduction, difficulty paying bills, and fear of losing their home, but inversely associated with transitioning to remote work. Parents of non-Hispanic (NH) Black children experienced greater employment reduction compared to parents of NH White children (1.9 [1.1, 3.0]). Parents from racial and ethnic minority groups were more likely to experience difficulty paying bills and fear losing their home, relative to NH White parents. Caregivers of children with CBCL scores in the clinical range were more likely to fear losing their home (2.1 [1.3, 3.4]).

Conclusion: These findings suggest that families of children with autism, families of lower socio-economic status, and families of racial and ethnic minority groups experienced fewer work flexibilities and greater financial distress during the pandemic. Future research can be used to assess if these impacts are sustained over time.

KEYWORDS

COVID-19, autism spectrum disorder, neurodevelopmental disorder, COVID-19 pandemic impacts, family impacts

1 Introduction

In March of 2020, a nationwide emergency was declared in the United States in an effort to control the spread of the coronavirus disease (COVID-19) (1). Many jurisdictions enacted stay-at-home orders, recommended quarantine protocols for healthy contacts of infected individuals, restricted personal travel, and temporarily closed non-essential businesses (2). These measures had vast socio-economic implications. Notably, the national unemployment rate increased to 13% from 3.8% at the beginning of the pandemic, with women losing employment at a significantly higher rate than men (3). The pandemic was also associated with increases in reported anxiety and depression and decreases in social participation and financial well-being (4).

Families of young children with autism and other developmental disabilities (DD) may have been more negatively affected by the pandemic restrictions than those of typically developing children. Autism is a neurodevelopmental disorder that is characterized by difficulties with social communication and social interaction as well as restricted and repetitive patterns in behaviors, interests, and activities (5). Children with autism may have a broad range of difficulties, including a strong preference for sameness, behavioral problems, and a need for assistance with activities of daily living. These difficulties may contribute to the higher levels of stress (6), depression and anxiety (7), and employment or financial insecurity (8, 9) reported by parents of children with autism. To mitigate these difficulties, many children with autism and other DDs see allied health professionals to help with addressing their various needs (10). Public health measures put in place to control the spread of COVID-19 disrupted the ability of some families to attend these appointments (11–13). Thus, the COVID-19 pandemic had the potential to exacerbate the potential stressors surrounding families of children with autism and other DDs.

Due to the recency of the COVID-19 pandemic, literature on its impact on families of children with autism or another DD is limited (14, 15). Some studies have documented intensified psychological and behavioral symptoms in children with autism (16–19), which could potentially be associated with increased parental stress or depression (17, 18, 20, 21). Several studies have found the COVID-19 pandemic to be associated with decreased quality of life or well-being for autistic individuals and their families (16, 22) and increased financial burden (21, 23), particularly in Black families (24). Other studies had conflicting results, with some families reporting perceived benefits of remote work or experiencing the pandemic as a welcome break, and others reporting that adjusting to the new normal with an autistic child exacerbated pre-existing challenges (25, 26). To facilitate effective planning for future public health emergencies, further research can help in understanding how families of children with autism as well as other DDs fared during the COVID-19 pandemic.

This study aimed to fill the aforementioned gaps in knowledge by surveying three groups of families of young children: those with a child with autism, those with a child with another DD, and those with a child sampled from the general population (POP). Our primary objectives were to identify differential impacts of the COVID-19 pandemic related to childcare, parental employment, and household financial security by group. We hypothesized that: (1) the impacts would be greater for families of children with autism or another DD than for POP children; (2) lower levels of socioeconomic status before the pandemic would exacerbate the adverse effects of the pandemic on families of children with disabilities; and (3) higher levels of child behavioral and emotional problems reported by parents would be associated with greater adverse impacts of the pandemic on families.

2 Methods

2.1 Study sample

Participants in this study originally completed the Study to Explore Early Development, Phase 3 (SEED3), a case-control study of young children funded by the Centers for Disease Control and Prevention (CDC) and implemented during 2017-2020 in six communities across the United States (Colorado, Georgia, Maryland, Missouri, North Carolina, and Wisconsin). SEED3 aimed to increase the understanding of autism and other DDs through the study of risk factors, co-occurring conditions, and behavioral phenotypes. Children were eligible for SEED3 if they were 2-5 years old, born and resided in the geographic study catchment area, and consistently lived with their biological mother from 6 months of age (or younger); additionally, the mother had to be able to communicate in English (or Spanish in the Colorado site). The mother participated in an extensive interview about sociodemographic characteristics, parental and child medical history, and services or treatments received. Additionally, several standardized assessments were performed by clinicians or completed by the mother.

Three groups of children were included: 1) children with autism; 2) children with another DD; and 3) POP children, as identified during their original participation in SEED3. Children were ascertained for potential inclusion in the autism or DD groups through sources serving or evaluating children with developmental difficulties, including but not limited to early intervention, special education, hospitals, and clinics. Participants who had previously received either an autism diagnosis from a clinical provider, or services for autism through early intervention or special education, or who scored ≥11 on the Social Communication Questionnaire (27) at enrollment, received a comprehensive developmental evaluation. A final autism classification was based on results from the Autism Diagnostic Observation Schedule (ADOS) (28, 29) and the Autism Diagnostic Interview-Revised (ADIR) (30, 31), administered in-person by research reliable clinicians. POP group children were identified through random sampling of birth records in the pre-specified birthdate geographic range at delivery. Prior publications document detailed descriptions of SEED eligibility criteria, enrollment methods, study group classification, and data collection (32–34).

The COVID-19 Impact Assessment was developed in 2020 to evaluate how changes related to the COVID-19 pandemic impacted children in SEED3 and their families. The 110-item questionnaire assessed changes in services and treatments, impacts on child development, changes in household routines, and impacts on household finances or parental employment during the pandemic in 2020. Families who completed SEED3 prior to March 31, 2020 were invited to participate in the COVID-19 Impact Assessment. Eligible families received the COVID-19 Impact survey along with a parent-report version of the Child Behavior Checklist (CBCL) (35) via mail and completed the items between January and June 2021. Parents who did not initially return the survey were contacted and provided with the option to complete the survey over the phone. The COVID-19 Impact Assessment was completed by the biological mother or father or another knowledgeable caregiver (hereinafter "parent" as 97.4% were completed by the mother or father).

The SEED3 protocol was approved by the CDC Institutional Review Board (IRB) and IRBs at each study site. In December 2020, the COVID-19 Impact Assessment was approved as an amendment to the SEED3 protocol. Reporting for this study was based on the Strengthening the Reporting of Observational Studies in Epidemiology guidelines (36).

2.2 Measures

All measures come from caregiver responses to the COVID-19 Impact Assessment. This assessment is published online (https://omb.report/icr/202102-0920-008/doc/108634700.pdf).

2.2.1 Changes to childcare

Parents who reported having any type of childcare during January or February of 2020 were asked if changes related to COVID affected their regular childcare during 2020. This was a dichotomous variable in which respondents could report yes or no. Due to the skip pattern, those who did not have childcare pre-COVID did not answer this question and were not included in this outcome measure.

2.2.2 Changes to parental employment

2.2.2.1 Employment reduction

Parents who responded that they had a paying job in January or February of 2020 were asked if they lost their job permanently, temporarily, or had their work hours reduced due to changes related to COVID in 2020. If the respondent had a spouse or partner with a paying job during January or February of 2020, they were similarly asked if their spouse or partner lost their job permanently, temporarily, or had their work hours reduced due to changes related to COVID in 2020. Each question was reported as a dichotomous (yes or no) answer. Provided that either the respondent or their spouse or partner had a paying job in January or February of 2020, a 'yes' response to any of the questions above was coded as having employment reduced. If the parent responded 'no' to all the questions, they were coded as not having their employment reduced due to changes related to COVID. Parents who did not have a paying job in January or February 2020 and did not have a partner or did not have a partner who had a paying job in January or February 2020 were not included in this outcome measure.

2.2.2.2 Increased remote work

Respondents with paying jobs in January or February 2020 were also asked if they either transitioned to remote work or increased hours worked remotely or from home due to COVID-related changes in 2020. Again, if the respondent had a spouse or partner with a paying job during January or February of 2020, they were asked the same questions. These four questions were consolidated into one variable, with a 'yes' response indicating that either the respondent or their partner either began working from home or increased hours worked from home. If all questions elicited 'no' responses, the respondent was coded as not working from home due to changes related to COVID. Respondents who did not have a paying job in January or February 2020 and did not have a partner or they had a partner who also did not have a paying job in January or February 2020 were not included in this outcome measure.

2.2.3 Changes to household income

2.2.3.1 Difficulty paying bills

Parents were asked how often they had difficulty paying their bills for each season of 2020 (i.e., pre-COVID: January-February; Spring: March-May; Summer: June-August; Fall: September-December). Response options were never, rarely, sometimes, very often, or extremely often. Never and rarely responses were combined, as were sometimes to extremely often due to small sample sizes. The seasons after the onset of the COVID-19 pandemic (Spring, Summer, and Fall) were also collapsed to gain an overall understanding of impacts during the pandemic. The response indicating the highest recorded difficulty throughout the seasons of the pandemic was used when consolidating variables.

2.2.3.2 Fear of losing home

Parents were asked how often in each season of 2020 they feared they might lose their home due to a lack of money. Response options fell on a 5-point Likert scale ranging from never to extremely often. Binary coding for analytic purposes combined never with rarely responses versus sometimes to extremely often responses. Questions inquiring about fear during the Spring, Summer, and Fall were combined to form a variable indicating fear throughout the pandemic, with the response option indicating the highest frequency being reported for the variable.

2.2.4 Child behavior checklist

The CBCL was completed by parents who received the invitation to participate in the COVID-19 Impact Assessment to determine the presence or absence of behavioral and emotional problems during the pandemic (35). Respondents were asked to characterize a list of child behaviors as "not true," "somewhat or sometimes true," or "very true or often true" for children ages 1.5-5. Parents completing the CBCL version for children 6-8 years characterized a list of child behaviors as "below average," "average," or "above average" compared to other children of the same age. Responses formed two broad scales: internalizing behavior problems and externalizing behavior problems, which made up an overall total problems scale. For this analysis, T-scores for total behavior problems (mean = 50, SD = 10) were converted to a binary variable. Scores of ≥60 indicate borderline to clinically significant behavior problems and scores <60 indicate no behavior problems compared to other children the same age.

2.3 Statistical analysis

Study sample characteristics were reported as numbers of observations (percentages) for categorical variables and means (standard deviations) for continuous variables. To assess differences between the autism, DD, and POP groups, likelihood ratio chi-square tests were performed for nominal descriptive variables, Mantel-Haenszel chi-square tests for ordinal variables, and one-way ANOVAs for continuous variables. Multivariable logistic regression was performed to assess associations between group status and impacts of the pandemic on parental employment (employment reduction and increased remote work) and household income related variables (difficulty paying bills and fear of losing home). Covariates for adjustment included group status (autism, DD, POP), family income at SEED3 relative to the federal poverty level (FPL) as a four-level categorical variable, child's race and ethnicity, and binary CBCL Total Problems t-score. To evaluate potential effect modification by household income and behavioral problems, we performed logistic regression analyses stratified by the respective potential modifiers. We tested for an interaction between group status and household income relative to the FPL at SEED3 as well as between group status and binary CBCL Total Problems t-score. Bayesian information criteria (37) indicated that the models without interaction terms better fit the data and likelihood ratio tests were insignificant for most interaction terms (data not shown). Adjusted analyses were conducted using complete case analysis, removing 28 individuals (2.7%) with incomplete covariates.

Statistical analyses were performed using SAS software, Version 9.4 (38). All tests of statistical significance were two-tailed and a p-value of less than 0.05 was considered statistically significant.

3 Results

3.1 Sample characteristics

Of the 1,789 families from SEED3 invited to participate in the COVID-19 Impact assessment, 1,027 parents completed the survey (57.4%). Distribution of some key demographic characteristics stratified by study group are outlined in Table 1. At SEED3, children from the autism, DD, and POP groups significantly differed by demographic characteristics including, sex ($p<0.0001$), race and ethnicity ($p=0.0018$), and age ($p<0.0001$). Additionally,

TABLE 1 Key characteristics of the Study to Explore Early Development COVID-19 Impact Assessment analytical sample.

	Autism (n = 274)	DD (n = 368)	POP (n = 385)	p-value[a]
Child sex, n (%)				<0.0001
Male	217 (79.2)	232 (63.0)	200 (52.0)	
Female	57 (20.8)	136 (37.0)	185 (48.1)	
Child race and ethnicity[b], n (%)				0.0018
Hispanic	35 (12.8)	42 (11.4)	39 (10.1)	
NH, Black	41 (15.0)	43 (11.7)	24 (6.2)	
NH, Other or Multiracial	40 (14.6)	40 (10.9)	44 (11.4)	
NH, White	158 (57.7)	243 (66.0)	278 (72.2)	
Child age in years, mean (SD)				
At SEED3, from September 2017-March 2020	3.9 (0.7)	4.1 (0.8)	3.7 (0.7)	<0.0001
At COVID-19 Impact Assessment, from January-July 2021	6.1 (0.8)	6.2 (0.8)	6.1 (0.7)	0.1494
Maternal education at baseline, n (%)				<0.0001
< High school degree	<10	<10	<10	
High school degree	43 (15.7)	28 (7.6)	13 (3.4)	
Some college	81 (29.6)	63 (17.1)	61 (15.8)	
College graduate	89 (32.5)	118 (32.1)	136 (35.3)	
Advanced degree	52 (19.0)	150 (40.8)	171 (44.4)	
Missing	<10	<10	<10	
Household income relative to the FPL at SEED3, n (%)				<0.0001
≤138% FPL	72 (26.3)	58 (15.8)	28 (7.3)	
>138 to ≤250% FPL	58 (21.2)	56 (15.2)	76 (19.7)	
>250 to 400% FPL	84 (30.7)	112 (30.4)	113 (29.4)	
≥400% FPL	54 (19.7)	130 (35.3)	163 (42.3)	
Missing	<10	12 (3.3)	<10	
Health insurance status at SEED3, n (%)				<0.0001
Public insurance	100 (36.5)	76 (20.7)	57 (14.8)	
Private insurance	125 (45.6)	268 (72.8)	314 (81.6)	
Public & private insurance	47 (17.2)	23 (6.3)	<10	
No insurance	<10	<10	<10	
Health insurance changes at COVID-19 Impact Assessment, n (%)				0.2955
No change	260 (94.9)	351 (95.4)	355 (92.2)	
Increased coverage	<10	<10	10 (2.6)	
Decreased coverage	<10	11 (3.0)	20 (5.2)	
Study site, n (%)				0.0082
Colorado	39 (14.2)	52 (14.1)	79 (20.5)	
Georgi	31 (11.3)	59 (16.0)	35 (9.1)	
Maryland	39 (14.2)	35 (9.5)	40 (10.4)	

(Continued)

TABLE 1 Continued

	Autism (n = 274)	DD (n = 368)	POP (n = 385)	p-value[a]
Missouri	59 (21.5)	61 (16.6)	82 (21.3)	
North Carolina	43 (15.7)	78 (21.2)	59 (15.3)	
Wisconsin	63 (23.0)	83 (22.6)	90 (23.4)	

n, sample size; DD, other developmental disabilities; POP, population comparison group; NH, non-Hispanic; SD, standard deviation.

[a] Likelihood ratio chi-square tests were used to calculate p-values for nominal descriptive variables, Mantel-Haenszel chi-square tests for differences in ordinal variables, and one-way ANOVA for continuous variables.

[b] Race and ethnicity data were collected by parent self-report and vital statistics/birth record data. Due to small sample sizes, American Indian/Alaska Native, Asian/Pacific Islander, or other race were combined into the NH other or multiracial race category.

groups at SEED3 significantly differed by maternal education ($p<0.0001$), household income relative to the FPL ($p<0.0001$), health insurance status ($p<0.0001$) and study site ($p=0.0082$). There was not a statistically significant difference in the change in health insurance coverage between groups at the COVID-19 Impact Assessment ($p=0.2955$).

3.2 Childcare changes

In January and February of 2020, 89.4% (autism group) to 92.9% (DD group) of the children in the study population attended a school or preschool outside of the home (Table 2). This percentage was not statistically different by group status ($p=0.2903$). However,

TABLE 2 Childcare, parental employment, and household income: Pre-COVID-19 and changes during the pandemic, Study to Explore Early Development COVID-19 Impact Assessment.

	Autism (n = 274)	DD (n = 368)	POP (n = 385)	p-value[a]
	n (%)	n (%)	n (%)	
Childcare changes				
Pre-COVID, child attended school/preschool	245 (89.4)	342 (92.9)	353 (91.7)	0.2903
Pre-COVID, family had other non-school childcare	77 (28.2)	157 (42.7)	170 (44.2)	<0.0001
Of those with childcare pre-COVID, changes related to COVID affected regular childcare	68 (88.3)	138 (88.5)	156 (91.8)	0.5395
Parental employment changes				
Paying job pre-COVID	255 (93.1)	355 (96.5)	377 (97.9)	0.0077
Employment reduction	118 (46.3)	129 (36.3)	156 (41.4)	0.0463
Increased remote work	149 (58.4)	248 (69.9)	294 (78.0)	<0.0001
Household Income Changes				
Difficulty paying bills, pre-COVID				<0.0001
Never or rarely	211 (77.0)	320 (87.0)	363 (94.3)	
Sometimes, very, or extremely often	63 (23.0)	48 (13.0)	22 (5.7)	
Difficulty paying bills during the pandemic in 2020				<0.0001
Never or rarely	175 (63.9)	278 (75.5)	331 (86.0)	
Sometimes, very, or extremely often	99 (36.1)	90 (24.5)	54 (14.0)	
Fear of losing home due to lack of money, pre-COVID				0.0019
Never or rarely	245 (89.7)	350 (95.1)	371 (96.4)	
Sometimes, very, or extremely often	28 (10.3)	18 (4.9)	14 (3.6)	
Fear of losing home during the pandemic in 2020				0.0002
Never or rarely	218 (79.9)	328 (89.1)	348 (90.4)	
Sometimes, very, or extremely often	55 (20.2)	40 (10.9)	37 (9.6)	

n, sample size; DD, other developmental disability; POP, population comparison group.

[a] Likelihood ratio chi-square tests were used to calculate p-values.

not including preschool or school, only 28.2% of families of a child with autism reported having childcare in January or February 2020 before the onset of the COVID-19 pandemic, which was lower than families of children in the DD (42.7%) or POP (44.2%) groups. Despite a smaller percentage of families of children with autism reporting having childcare pre-COVID, a high percentage of participants in all groups responded that changes related to COVID affected their regular childcare (88.3%-91.8%; p=0.5395). Due to a small number of families with childcare pre-pandemic responding that their childcare was not affected by COVID, investigations by socioeconomic status or emotional and behavioral problems could not be made.

3.3 Parental employment changes

In the study sample, only 40 respondents reported neither they nor their partner had a paying job in January or February of 2020; 30 of these individuals reported not having a partner. There was a significant difference in the distribution of parents having a paying job by study group (Table 2, p=0.0077); families of children with autism had the lowest percentage, though for all three groups over 90% of respondents had a paying job pre-COVID. Nonetheless, participants in the autism group reported the greatest percentage of reduced work hours, permanently losing their job, or temporarily losing their job, due to changes related to COVID-19 in 2020 (46.3%). Parents also reported working remotely or from home at different percentages by group (p<0.0001), with parents of children with autism reporting the lowest percentage (58.4%), followed by parents of children with other DDs (69.9%), then parents of children in the POP group (78.0%).

However, in adjusted models, individuals in the DD group had significantly lower odds of reduced employment compared to the POP group (Table 3, aOR [95% CI] = 0.7 [0.5, 0.9]), but there was no significant difference in employment reduction between the autism and POP groups (0.8 [0.6, 1.2]). Families with lower household income experienced a significantly higher odds of having reduced employment due to the pandemic with decreasing household income categories, relative to those with a household income ≥400% of the FPL (Table 3). By race-ethnicity, parents of NH Black children had 90% higher odds of having reduced employment due to the pandemic, compared to NH White parents (1.9 [1.1, 3.0]). After adjustment for covariates, no difference was observed in employment reduction among families with children with and without behavioral problems as measured by the CBCL (1.2 [0.9, 1.7]).

Respondents in the autism and DD groups who reported having a paying job or a partner with a paying job in January or February of 2020, had lower odds of beginning to work remotely or from home or increasing hours worked remotely or from home (autism group: 0.4 [0.3, 0.6], DD group: 0.7 [0.5, 0.9]) relative to the POP group. These results were attenuated after adjusting for covariates (0.6 [0.4,

TABLE 3 Odds ratios for parental employment changes during 2020 of the COVID-19 pandemic, Study to Explore Early Development COVID-19 Impact Assessment.

Variable	Respondent or partner had a paying job, pre-COVID	Employment reduction: respondent or partner reduced work hours, or lost job permanently or temporarily			Increased remote work: respondent or partner started working remotely or increased hours working remotely		
	N (% yes)	N (% yes)	Unadjusted OR (95% CI)	Adjusted OR^a (95% CI)	N (% yes)	Unadjusted OR (95% CI)	Adjusted OR^a (95% CI)
Group status							
Autism	255 (93.1)	118 (46.3)	1.2 (0.9, 1.7)	0.8 (0.6, 1.2)	149 (58.4)	**0.4 (0.3, 0.6)**	**0.6 (0.4, 1.0)**
DD	355 (96.5)	129 (36.3)	0.8 (0.6, 1.1)	**0.7 (0.5, 0.9)**	248 (69.9)	**0.7 (0.5, 0.9)**	0.8 (0.5, 1.2)
POP	377 (97.9)	156 (41.4)	1.0	1.0	294 (78.0)	1.0	1.0
Income							
≤138% FPL	128 (81.0)	77 (60.2)	**3.3 (2.2, 5.1)**	**3.0 (1.9, 4.8)**	28 (21.9)	**<0.1 (0.0, 0.1)**	**<0.1 (0.0, 0.1)**
>138 to ≤250% FPL	186 (97.9)	88 (47.3)	**2.0 (1.4, 2.9)**	**1.9 (1.3, 2.7)**	105 (56.5)	**0.2 (0.1, 0.3)**	**0.2 (0.1, 0.3)**
>250 to 400% FPL	308 (99.7)	120 (39.0)	**1.4 (1.0, 1.9)**	**1.4 (1.0, 2.0)**	245 (79.6)	**0.6 (0.4, 0.9)**	**0.6 (0.4, 0.9)**
≥400% FPL	343 (98.9)	107 (31.2)	1.0	1.0	300 (87.5)	1.0	1.0
Race and ethnicity^b							
Hispanic	111 (95.7)	45 (40.5)	1.1 (0.8, 1.7)	0.9 (0.6, 1.3)	67 (60.4)	**0.5 (0.3, 0.8)**	1.0 (0.6, 1.6)

(Continued)

TABLE 3 Continued

Variable	Respondent or partner had a paying job, pre-COVID	Employment reduction: respondent or partner reduced work hours, or lost job permanently or temporarily			Increased remote work: respondent or partner started working remotely or increased hours working remotely		
	N (% yes)	N (% yes)	Unadjusted OR (95% CI)	Adjusted OR^a (95% CI)	N (% yes)	Unadjusted OR (95% CI)	Adjusted OR^a (95% CI)
NH, Black	94 (87.0)	58 (61.7)	**2.7 (1.7, 4.2)**	**1.9 (1.1, 3.0)**	45 (47.9)	**0.3 (0.2, 0.5)**	0.6 (0.4, 1.1)
NH, Other or Multiracial	116 (93.6)	50 (43.1)	1.3 (0.8, 1.9)	1.2 (0.8, 1.8)	78 (67.2)	0.7 (0.4, 1.0)	0.7 (0.4, 1.1)
NH, White	666 (98.1)	250 (37.5)	1.0	1.0	501 (75.2)	1.0	1.0
CBCL Total Score							
≥60 Clinical range	272 (92.2)	129 (47.4)	**1.5 (1.1, 1.9)**	1.2 (0.9, 1.7)	164 (60.3)	**0.5 (0.4, 0.7)**	1.1 (0.8, 1.7)
<60 Normal range	711 (97.7)	271 (38.1)	1.0	1.0	524 (73.7)	1.0	1.0

OR, odds ratio; CI, confidence interval; ASD, autism spectrum disorder; DD, other developmental disability; POP, population control participants; FPL, Federal Poverty Line; NH, Non-Hispanic; CBCL, Child Behavior Checklist.

[a] Odds ratios presented by each variable (group status, 4-category income relative to the federal poverty level, race and ethnicity, and binary CBCL total score) are adjusted for the remaining variables listed in the table.

[b] Due to small sample sizes, Asian or Pacific Islander/Native Hawaiian, American Indian/Alaskan Native, those reporting another race, or of multiple races were combined to form the NH Other or Multiracial category.

Bold indicates statistical significance at alpha = 0.05.

1.0] for the autism group and 0.8 [0.5, 1.2] for the DD group). Each income category below 400% of the FPL had significantly lower odds of increasing remote work hours with the COVID-19 pandemic (Table 3). After adjusting for covariates, no differences were observed between increased remote work in minority families relative to NH White families, or between families of children with or without clinically significant CBCL scores.

3.4 Household income changes

Pre-COVID and during the COVID-19 pandemic, higher percentages of respondents with a child in the autism and DD groups reported having difficulty paying bills sometimes, very, or extremely often compared to the POP group (Table 2). Table 4 depicts the unadjusted and covariate-adjusted results from the multivariable logistic regression models for difficulty paying bills during the COVID-19 pandemic in 2020. After adjusting for covariates, families of children in the autism group had 80% higher odds (1.8 [1.2, 2.9]) of reporting difficulty paying bills during the pandemic compared to the POP group. Similarly, families of children with other DDs had 60% higher odds of reporting difficulty paying bills during the pandemic compared to the POP group after adjustment (1.6 [1.0, 2.5]). By income, those with the lowest income relative to the FPL at SEED3 had the highest odds of difficulty paying bills (12.6 [7.3, 22.0]). Furthermore, each household income category relative to the FPL had significantly higher odds of difficulty paying bills during the pandemic compared to those with income ≥400% FPL, with decreasing magnitude as income increased (Table 4). Parents from racial and ethnic minority groups were more likely to experience difficulty paying bills during the pandemic, with parents of NH Black children experiencing the most difficulty compared to NH White children (3.6 [2.2, 6.0]). After adjustment for covariates, difficulty paying bills during the pandemic did not differ between families of a child with a clinically significant CBCL score relative to those with a child with a CBCL score <60 (1.3 [0.9, 1.9]).

The percentages of respondents who reported that they feared losing their home sometimes, very, or extremely often during the COVID-19 pandemic differed across groups, with the highest percentage in the autism group (20.2%) and the lowest percentage in the POP group (9.6%, Table 2). After adjusting for covariates, there was no significant difference in fear of losing one's home during the COVID-19 pandemic between the autism (0.9 [0.5, 1.6]) or DD (0.7 [0.4, 1.3]) groups relative to the POP group. Relative to families with a household income ≥400% of the FPL, families of lower income had higher odds of being fearful of losing their home during the pandemic, with increasing magnitude as household income decreased (Table 4). Families from racial and ethnic minority groups were more fearful of losing their homes during the pandemic compared to families of NH White children, after adjusting for covariates (Table 4). Caregivers of children who have clinically significant behavioral and emotional health problems had 2.1 times higher odds (95% CI: 1.3, 3.4) of being fearful of losing their home during the pandemic compared to those with children with CBCL score <60.

3.5 Potential effect modifiers

The odds ratios indicating impacts of the pandemic on families of children with autism relative to families in the POP group were similar for lower income (≤200% FPL) and higher income (>200% FPL) families (Table 5). In contrast, the odds ratios comparing the DD group to the POP group differed somewhat by income level. In

TABLE 4 Odds ratios for household income changes during 2020 of the COVID-19 pandemic, Study to Explore Early Development COVID-19 Impact Assessment.

	Difficulty paying bills				Fear of losing home			
Variable	Pre-COVID N (%)	Pandemic N (%)	Unadjusted OR (95% CI)	Adjusted OR[a] (95% CI)	Pre-COVID N (%)	Pandemic N (%)	Unadjusted OR (95% CI)	Adjusted OR[a] (95% CI)
Group Status								
Autism	63 (23.0)	99 (36.1)	**3.5 (2.4, 5.1)**	**1.8 (1.2, 2.9)**	28 (10.3)	55 (20.2)	**2.4 (1.5, 3.7)**	0.9 (0.5, 1.6)
DD	48 (13.0)	90 (24.5)	**2.0 (1.4, 2.9)**	**1.6 (1.0, 2.5)**	18 (4.9)	40 (10.9)	1.1 (0.7, 1.8)	0.7 (0.4, 1.3)
POP	22 (5.7)	54 (14.0)	1.0	1.0	14 (3.6)	37 (9.6)	1.0	1.0
Income								
≤138% FPL	62 (39.2)	95 (60.1)	**20.3 (12.0, 34.2)**	**12.6 (7.3, 22.0)**	34 (21.7)	56 (35.7)	**18.7 (9.2, 38.0)**	**11.0 (5.2, 23.2)**
>138 to ≤ 250% FPL	34 (17.9)	63 (33.2)	**6.7 (4.0, 11.2)**	**5.9 (3.5, 10.1)**	11 (5.8)	29 (15.3)	**6.1 (2.9, 12.8)**	**5.0 (2.4, 10.8)**
>250 to 400% FPL	24 (7.8)	50 (16.2)	**2.6 (1.6, 4.3)**	**2.5 (1.5, 4.2)**	<10	30 (9.7)	**3.6 (1.7, 7.5)**	**3.5 (1.6, 7.3)**
≥400% FPL	<10	24 (6.9)	1.0	1.0	<10	10 (2.9)	1.0	1.0
Race and Ethnicity[b]								
Hispanic	22 (19.0)	39 (33.6)	**2.6 (1.7, 4.1)**	1.5 (0.9, 2.5)	10 (8.6)	23 (19.8)	**3.2 (1.8, 5.5)**	**2.0 (1.1, 3.6)**
NH, Black	41 (38.0)	63 (58.3)	**7.2 (4.7, 11.2)**	**3.6 (2.2, 6.0)**	27 (25.0)	38 (35.2)	**7.0 (4.3, 11.4)**	**3.8 (2.2, 6.7)**
NH, Other or Multiracial	12 (9.7)	31 (25.0)	**1.7 (1.1, 2.7)**	1.5 (0.9, 2.5)	<10	22 (17.7)	**2.8 (1.6, 4.8)**	**2.6 (1.4, 4.7)**
NH, White	58 (8.5)	110 (16.2)	1.0	1.0	16 (2.4)	49 (7.2)	1.0	1.0
CBCL Total Score								
≥60 Clinical range	70 (23.7)	107 (36.3)	**2.5 (1.9, 3.4)**	1.3 (0.9, 1.9)	39 (13.3)	69 (23.5)	**3.3 (2.3, 4.8)**	**2.1 (1.3, 3.4)**
<60 Normal range	62 (8.5)	134 (18.4)	1.0	1.0	20 (2.8)	62 (8.5)	1.0	1.0

OR, odds ratio; CI, confidence interval; ASD, autism spectrum disorder; DD, other developmental disability; POP, population control participants; FPL, Federal Poverty Line; NH, Non-Hispanic; CBCL, Child Behavior Checklist.

[a] Odds ratios presented by each variable (group status, 4-category income relative to the federal poverty level, race and ethnicity, and binary CBCL total score) are adjusted for the remaining variables listed in the table.

[b] Due to small sample sizes, Asian or Pacific Islander/Native Hawaiian, American Indian/Alaskan Native, those reporting another race, or those reporting more than one race were combined to form the non-Hispanic Other or Multiracial category.

Bold indicates statistical significance at alpha = 0.05.

families of higher income, the DD group was less likely to experience employment reduction compared to the POP group (0.6 [0.4, 0.9]), whereas in lower income families, parents of children with other DDs had similar employment reduction compared to the POP group (1.1 [0.5, 2.3]). Additionally, in lower income families, those in the DD group had an increased odds of difficulty paying bills (2.2 [1.1, 4.4]) compared to families of children in the POP group, whereas, among higher income families, the odds of having difficulty paying bills was similar in the DD and POP groups (1.3 [0.8, 2.2]). The likelihood ratio test for the group status by household income interaction was only statistically significant for the logistic regression model examining parents who increased remote work during the pandemic (p=0.0422). However, model coefficients and resulting odds ratios were similar with or without the inclusion of this interaction term (data not shown).

We found no evidence of effect modification in analyses stratified by CBCL Total Problems t-score categories (Table 6). In families of children with autism and families of children with other DDs compared to the POP group, the odds ratios were largely similar for families of children with typical CBCL scores (<60) and those scoring in the borderline to clinically significant range (≥60). For each outcome, likelihood ratio tests for the interaction between binary CBCL Total Problems t-score and group status were not statistically significant (data not shown).

4 Discussion

Our study examined impacts of the COVID-19 pandemic on measures of childcare, parental employment, and household income on a sample of families of three groups of children: those

TABLE 5 Odds ratios relative to the POP group for parental employment changes and household income changes during 2020 of the COVID-19 pandemic stratified by binary household income at SEED3, Study to Explore Early Development COVID-19 Impact Assessment .

	Autism		DD	
	≤200% FPL aOR[a] (95% CI)	>200% FPL aOR (95% CI)	≤200% FPL aOR (95% CI)	>200% FPL aOR (95% CI)
Employment reduction	0.8 (0.4, 1.6)	1.0 (0.7, 1.6)	1.1 (0.5, 2.3)	**0.6 (0.4, 0.9)**
Increased remote work	**0.5 (0.2, 1.0)**	0.6 (0.4, 1.1)	0.6 (0.3, 1.2)	0.9 (0.6, 1.4)
Difficulty paying bills	**2.2 (1.1, 4.5)**	**1.9 (1.0, 3.4)**	**2.2 (1.1, 4.4)**	1.3 (0.8, 2.2)
Fear of losing home	1.2 (0.5, 2.7)	0.9 (0.4, 2.0)	1.0 (0.4, 2.2)	0.6 (0.3, 1.3)

POP, child sampled from the general population; SEED3, Study to Explore Early Development, Phase 3; DD, developmental disability; FPL, federal poverty level; aOR, adjusted odds ratio; CI, confidence interval, NH, non-Hispanic.

[a] Logistic regression models include the following covariates: group status (autism, DD, POP), child's race and ethnicity (NH Black, Hispanic, NH Other or Multiracial, NH White), and binary Child Behavior Checklist Total Problems t-score (≥60 or <60).

Bold indicates statistical significance at alpha <0.05.

with autism, those with another DD, and a population comparison group. Even after adjusting for household income, race and ethnicity, and the behavioral and emotional problems of the child, families of children with autism reported increased odds of difficulty paying bills and decreased odds of working remotely or from home compared to families of POP children. Targeted support systems may need to be established in anticipation of future emergency situations to assist vulnerable populations, including families of children with disabilities.

We found parents of children in the autism group were less likely to have a paying job and had greater difficulty paying bills prior to the onset of the pandemic, when compared to parents of children in the POP group. This finding is consistent with previous studies documenting the economic impacts of autism, including decreased parental employment and productivity due to therapy schedules and caregiving needs as well as the high out-of-pocket costs of autism services and the excess healthcare expenditures in general for children with autism relative to children without disabilities (39–45). However, our overall sample had a high frequency of parents with a paying job pre-COVID, as 93% of parents of children with autism reported having a paying job. Still, we attempted to mitigate potential confounding by adjusting for household income at SEED3. While some previous studies reported that parents of children with either autism or another DD had financial concerns due to the pandemic, these studies lacked a comparison group, making it difficult to determine if financial concerns were universal or associated with having a child with a DD (21, 23). Simply examining frequencies, each group had an elevated difficulty paying bills during the pandemic, which aligns with the findings of these studies.

We found that families of children with autism had 40% lower odds of working remotely or from home during the COVID-19 pandemic after adjusting for race and ethnicity, income, and behavioral and emotional problems, compared to families of POP children. Previous literature cites remote work and parenting a child with autism as increasing parental stress due to the difficulty of balancing work obligations and facilitating the child's therapies and schoolwork (23, 25), and parents who switched to working from home felt that the pandemic increased their responsibilities (46). This perceived increase in stress and responsibility may help explain why parents of children with autism were less likely to work from home during the pandemic in this study, though the data do not allow us to determine the reason for being less likely to work remotely. The increased demands on working parents with the COVID-19 pandemic were not specific to parents of children

TABLE 6 Odds ratios relative to the POP group for parental employment changes and household income changes during 2020 of the COVID-19 pandemic stratified by CBCL Total Problems binary score, Study to Explore Early Development COVID-19 Impact Assessment.

	Autism		DD	
	CBCL <60 aOR[a] (95% CI)	CBCL ≥60 aOR (95% CI)	CBCL <60 aOR (95% CI)	CBCL ≥60 aOR (95% CI)
Employment reduction	0.8 (0.5, 1.3)	0.7 (0.3, 1.6)	0.7 (0.5, 1.0)	0.5 (0.2, 1.2)
Increased remote work	0.6 (0.4, 1.0)	0.6 (0.2, 1.6)	0.9 (0.6, 1.3)	0.7 (0.2, 1.8)
Difficulty paying bills	**2.0 (1.1, 3.5)**	1.8 (0.7, 4.6)	1.5 (0.9, 2.5)	1.8 (0.7, 5.0)
Fear of losing home	1.0 (0.5, 2.1)	0.6 (0.2, 1.7)	0.9 (0.5, 1.8)	0.4 (0.1, 1.2)

POP, child sampled from the general population; CBCL, Child Behavior Checklist; DD, developmental disability; aOR, adjusted odds ratio; CI, confidence interval, NH, non-Hispanic.

[a] Logistic regression models include the following covariates: group status (autism, DD, POP), household income relative to the federal poverty level (FPL) at SEED3 (≤138% FPL, > 138 to ≤250% FPL, >250 to 400% FPL, ≥400% FPL), and child's race and ethnicity (NH Black, Hispanic, NH Other or Multiracial, NH White).

Bold indicates statistical significance at alpha <0.05.

with autism, as research indicates that many parents of children without disabilities also experienced difficulties balancing remote work and caregiving (47, 48). In developing preparations for future public health emergencies, it may be important to recognize that parents of children with autism may face additional challenges in working from home.

An abundance of research has documented how the pandemic disproportionately impacted lower income families (49–52). After adjusting for group status, race and ethnicity, and behavioral and emotional problems, families with a lower household income prior to the pandemic had significantly greater odds of employment reduction, difficulty paying bills, and fear of losing their home during the pandemic relative to families in the highest income category. There are likely additional factors that contributed to the disproportionate disadvantages faced by families with lower income that we could not measure. Individuals with a lower household income pre-pandemic also had lower odds of working remotely or from home than those with a higher household income. While it is possible that individuals of lower income were working jobs that could not be performed remotely, a lack of resources such as a computer or internet accessibility might have also served as a barrier.

We hypothesized lower levels of socioeconomic status before the pandemic would exacerbate the adverse effects of the pandemic on families of children with disabilities. However, we found little evidence that the impact of having a child with autism or other disabilities on COVID-related measures of parental employment and household income changes was greater for low income than high income families.

Several studies have highlighted the impacts of the pandemic on behavioral problems in children with autism (16–18, 53, 54). In light of this, we hypothesized that higher levels of child behavioral and emotional problems would be associated with greater adverse economic and employment impacts on their families during the pandemic. We found that families of children with behavioral problems in the clinical range were more than twice as likely to report fear of losing their home compared to families of children without behavioral problems. Prior to the pandemic, in non-emergency settings, research indicated that parental stress is a consequence and antecedent of child behavior problems, while simultaneously, child behavior problems are both an antecedent and consequence of parental stress (55). Evidence supporting this idea during the COVID-19 pandemic has been documented as the "spillover hypothesis" that suggests that high levels of stress or anxiety in parents can "spill over" to their children and lead to an increase in child behavior problems (56–58). It is possible that the increased economic stressors of the pandemic may have exacerbated the emotional and behavioral problems in children. It is also possible that parents who reported being fearful of losing their home had increased stress relative to those who were not fearful of losing their home. However, we did not find evidence that the economic impact of having a child with autism or other DD differed by the presence or absence of behavior problems in the child.

We found that families of racial and ethnic minority groups experienced greater adverse economic impacts than other families. These findings align with previous research suggesting that Black and Hispanic individuals had more frequent job or wage loss and more trouble paying bills compared to White individuals during the pandemic (59–61). The disproportionate socioeconomic impact of the COVID-19 pandemic on racial and ethnic minority groups may have only worsened the disparities that are already present (62). Initiatives to assist communities that may experience disproportionate impacts may help mitigate the heightened negative impacts in future public health emergencies.

4.1 Limitations

At SEED3, the groups were not balanced on key variables of interest, with families of children in the autism and DD groups being of a lower socioeconomic status than families of POP children. We attempted to eliminate the potential confounding by socioeconomic status by adjusting the models for household income at SEED3, but residual confounding is possible. Additionally, by conducting a complete case analysis, individuals who had missing data in any of the outcomes or covariates were excluded from the analysis. However, only 2.5% of the sample had a missing variable so it is likely that the results would remain unchanged if these individuals were to be included. Finally, our analyses relied on self-reported measures of employment and income changes during 2020 from the COVID-19 Impact Assessment which was completed between January and June of 2021, which may have introduced measurement bias in the form of social desirability, recall bias, or errors in reporting.

4.2 Conclusion

Families of children with autism and other DDs may be especially vulnerable in public health emergencies. Using data from the COVID-19 Impact Assessment, we found that families of children with autism more often reported difficulty paying bills and lower odds of transitioning to remote work during 2020 of the pandemic compared to families of children sampled from the general population. We also found that families of lower socio-economic status as well as families of racial and ethnic minority groups experienced fewer work flexibilities and greater financial distress during the pandemic. Future research can help us better understand if these impacts are sustained over time and how best to support families who might lie at the intersection of these disadvantages during future emergency situations.

Data availability statement

The original data presented in this paper are protected to ensure participant confidentiality. Further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by The SEED3 protocol, CDC Institutional Review Board (IRB) and IRBs at each study site. In December 2020, the SEED3 COVID-19 Impact Assessment was approved as an amendment to the SEED3 protocol. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

OP: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. HC: Methodology, Supervision, Writing – review & editing. CD: Funding acquisition, Investigation, Supervision, Writing – review & editing. SF: Data curation, Investigation, Methodology, Validation, Writing – review & editing. EM: Writing – review & editing. CN: Investigation, Supervision, Writing – review & editing. KP: Funding acquisition, Investigation, Supervision, Writing – review & editing. JS: Writing – review & editing. LW: Investigation, Methodology, Supervision, Writing – review & editing. MD: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The findings and conclusions in this report are those of the authors and do not necessarily represent the view of the Centers for Disease Control and Prevention.

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EDITED BY
Cecilia Montiel Nava,
The University of Texas Rio Grande Valley,
United States

REVIEWED BY
Elisabetta Filomena Buonaguro,
University of Naples Federico II, Italy
Anna Urbanowicz,
Deakin Unviversity, Australia

*CORRESPONDENCE
Fouad A. Alshaban
✉ falshaban@hbku.edu.qa

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Effects of COVID-19 on Autism Spectrum Disorder in Qatar

Fouad A. Alshaban[1,2]*, Iman Ghazal[1], Sanaa T. Al-Harahsheh[3], Mustafa Lotfy[4], Hawraa Al-Shammari[1], Fatema Al-Faraj[1], I. Richard Thompson[1], Allison B. Ratto[5], Assal Nasir[6] and Mohamed Tolefat[7]

[1]Qatar Biomedical Research Institute, Hamad bin Khalifa University, Doha, Qatar, [2]College of Health and Life Sciences, Hamad Bin Khalifa University, Doha, Qatar, [3]World Innovation Summit for Health (WISH), Qatar Foundation, Doha, Qatar, [4]Community Outreach, Qatar Autism Family Association, Doha, Qatar, [5]Center for Autism Spectrum Disorders, Childrens National Health System, Rockville, MD, United States, [6]Department of Biological Sciences, Drexel University, Philadelphia, PA, United States, [7]Autism Department, Shafallah Center for Children with Disabilities, Doha, Qatar

Introduction: The unprecedented impact of the coronavirus pandemic (COVID-19) has had profound implications on the ASD community, including disrupting daily life, increasing stress and emotional dysregulation in autistic children, and worsening individual and family well-being.

Methods: This study used quantitative and qualitative survey data from parents in Qatar (n=271), to understand the impact of the COVID-19 pandemic on autistic children and their families in Qatar. The questionnaire was a combination of open-ended (qualitative) and closed-ended (quantitative) questions to explore patterns in the experiences of the different families, as well as to contrive themes. The survey was created in a way to evaluate the psychological, academic/intervention, economic, and other impacts of the pandemic related measures on a sample of multicultural families residing in the State of Qatar during the peak period of confinement and physical distancing in 2020. Data acquisition involved the utilization of Google Forms. Subsequent quantitative analysis employed the SPSS software and chi-square analysis for numerical examination, enabling the characterization of the studied population and exploration of associations between parental stress levels and variables such as employment status, therapy accessibility, presence of hired assistance, and alterations in their childs skills. Concurrently, qualitative data from written responses underwent thorough categorization, encompassing themes such as emotional isolation, mental or financial challenges, and difficulties in obtaining support.

Results: Parents expressed distress and disturbance in their daily lives, including profound disruptions to their childrens access to treatment, education, and activities. Most parents reported deteriorations in their childrens sleep (69.4%), behavioral regulation (52.8%), and acquired skills across multiple domains (54.2%). Parents also reported decreased access to family and social support networks, as well as decreased quality of clinical and community support.

Qualitative analysis of parental responses revealed that child developmental regression was an important source of parental stress.

Discussion and conclusion: The greater impact of the pandemic on autistic children and their families emphasizes the need for accessible and affordable health, education, and family services to manage their special needs.

KEYWORDS

COVID-19, social restrictions, ASD, stress, support

Introduction

There is no doubt that the COVID-19 pandemic, which has rapidly swept through the world, has affected nearly all aspects of life; including the health and safety of all people, especially individuals affected by acute and chronic illnesses. Individuals with neurodevelopmental disorders such as Autism Spectrum Disorder (ASD) are no less immune to the direct and indirect impacts of this pandemic. Early data suggests that people with developmental disabilities may be even more susceptible to adverse health outcomes and death from COVID-19 (1, 2). Measures taken by most countries to control and limit the spread of COVID-19 included the closure of schools and centers providing treatment, rehabilitation, educational and training services. Nonetheless, efforts were made by most service providers to find alternative ways to compensate, even partially, for these restrictions to alleviate the great burden on families of autistic individuals. While the measures taken by countries to control and limit the spread of COVID-19 are myriad in number, they can be addressed in the following categories: impact on 1) the provision of health care services, including diagnostic, treatment, and rehabilitation services; 2) educational services; 3) autistic individuals and their families; 4) medical and intervention service providers; and 5) ASD research.

ASD is characterized by pervasive impairments in social reciprocity, communication, stereotyped behaviors, and restricted interests (3). Diagnosis of ASD requires a multidisciplinary assessment by healthcare service providers. Before the COVID-19 pandemic, centers and clinics around the world, including in Qatar, usually had a long waiting list for assessment (4). With the rise of this pandemic, many of these services were interrupted for varying periods, forcing families to postpone diagnostic evaluations, in turn negatively affecting the outcome of any intervention for the child, as earlier diagnosis is strongly associated with positive lifelong outcomes for autistic individuals (5–9). Early intervention (implemented before the age of four) is associated with gains in cognition, language, adaptive behavior, social behavior, and overall quality of life for both the child and the family (10–13).

The COVID-19 pandemic has exacerbated health inequalities and increased mental health problems on a worldwide scale. Many studies have been published recently that report increased mental health challenges across multiple study settings (e.g. USA, England, India, Lebanon, Qatar, Singapore, etc.) imposed by COVID-19 (14–17), including specifically among autistic children (18). There has also been a "silver lining" of increased access to telehealth services, which long-term may address underlying disparities in healthcare systems through the dissemination of more sustainable and equitable practices for delivering efficient mental healthcare services (19). An online survey of ASD professionals highlighted several vulnerability factors of autistic individuals in coping with the COVID-19 pandemic, including challenges related to core ASD characteristics, neuropsychological traits, executive functioning difficulties, and comorbid mental health problems all vulnerability factors reported by professionals (20). Results of initial research have indeed shown a significant negative impact of the COVID-19 pandemic on individuals with neurodevelopmental disorders such as ASD (21–23). Autistic individuals are particularly vulnerable to the disruptions caused by the COVID-19 pandemic. Lockdowns seeking to stem the spread of the pandemic led to closures of critical support institutions, such as schools, diagnostic and treatment clinics and agencies, and outpatient mental and medical healthcare, as well as support groups and organizations. Online learning, used widely to maintain access to education, has been an insufficient replacement for many autistic individuals, due to their need for specialized direct instruction and hands-on learning. One study examining the telehealth adaptation of cognitive-behavioral therapy (CBT) for anxiety in autistic children found challenges related to distractibility and reduced control of the environment, as well as decreased reciprocity and engagement in sessions (18). Attempts to provide online educational instruction for autistic students have also substantially increased demands on both educators and families to support students learning (24), often leaving families with little more than recommendations for how to provide instruction themselves (25). In addition to educational challenges, autistic individuals and their families are also impacted by reduced access to vocational training and support, home-based intervention, and access to invaluable outlets for leisure (26). Indeed, reduced independence and disruptions to routines were reported by most families of autistic children (26).

Yet the impacts of the pandemic may not be universally negative. One recent study on the psychological impact of the pandemic on autistic individuals in Spain, showed reduced psychopathology and stress and improved feeding on both caregiver-report and self-report, despite decreases in social interaction and face-to-face relationships, with particular benefits for young adults, perhaps due to reduced stressors related to these external relationships and demands (27). In contrast, caregivers reported increased levels of stress and anxiety for themselves. The contrast between the experiences of autistic individuals and those of their caregivers in this study may be at least partially attributable to the already high-stress levels for family members of autistic individuals before the pandemic (28–30). A study based in Saudi Arabia found that parents of autistic children reported increased stress and anxiety related to caring for their autistic children during the COVID-19 pandemic (31). Parents of younger children, and mothers in particular, reported the highest levels of anxiety, and parental anxiety and mental health together predicted perceived mental health needs. Parents of autistic children may be particularly vulnerable to the effects of the COVID-19 pandemic and associated lockdowns, to their pre-existing high-stress levels which make the added stresses faced by all parents (e.g., unemployment, working from home, caring for typically developing children engaging in online learning, reduced access to social supports) even more impactful.

The objective of the present study is to evaluate the effect of measures taken to control COVID-19 pandemic on the daily functioning and well-being of autistic individuals and their families in Qatar, a country that has made critical gains in recent decades in expanding access to ASD diagnosis and treatment. Specifically, this study investigates parent-reported impacts of COVID-19 mitigation measures (i.e., lockdowns restricting access to services and requiring families to remain at home) on the daily functioning of autistic children, access to services, and parent psychological well-being. We hypothesized that parental stress would be significantly associated with parent employment status, access to in-home therapy, access to specialized intervention, presence of hired help in the home (e.g., housekeeper, nanny, etc.), and regression in child skills. Of note, hired help in the home is relatively common in Qatar and these untrained individuals often provide substantial support to families in caring for autistic children in the home. Thus, this variable was important to include in this specific cultural context. The qualitative data not only allowed us to add more context to the individual situation of each family and provided an open view of the differences in experiences during that time but also played a crucial role in strengthening our study design and findings. By considering the qualitative data questions, we were able to gain more perspective and contrive additional information about the common and uncommon challenges parents faced during this period. This holistic approach, combining qualitative and quantitative data, contributes to a comprehensive understanding of the effects of COVID-19 mitigation measures on the daily functioning and well-being of autistic individuals and their families in Qatar. Examining the impact of COVID-19 on autistic children in Qatar is particularly vital, as it allows for a nuanced understanding of how cultural and contextual factors unique to the region may shape the experiences of families and individuals with autism.

Materials and methods

Study design

To examine and evaluate the effect of measures taken to control the COVID-19 pandemic on autistic individuals and their families, a mixed-method approach (32), collecting quantitative and qualitative survey data from parents of autistic children in Qatar was used. To collect the data, we created a questionnaire to be completed through Google Forms. The survey took place between September and December of 2020. The Participants gave their informed consent via the online platform or by email. This study was approved by Qatar Biomedical Research Institute Institutional Review Board (IRB) research ethics committee. All procedures performed were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Participants

A convenience sample of 271 parents who self-identified as having at least one child aged between 3 and 18 years with a formal ASD diagnosis was used. All families resided in the State of Qatar during the COVID-19 pandemic. Participants were recruited via online advertisement through various social media channels, organizations (e.g., Qatar Autism Society) and via existing databases of autistic individuals (33) that have previously given their consent to be contacted for ASD-related research. We contacted parents of children with the diagnosis of ASD by telephone or by e-mail (online form). Those with more than one autistic child were asked to focus on just one child (of their own choosing) in their responses.

Instruments

Google Forms was used to create an online parent survey to be shared through the dissemination of a hyperlink. All participants provided electronic informed consent that contained information about the purpose of the study, procedures, benefits of participating, voluntary participation, and contact information of the researchers. Since no questionnaire existed for evaluating the target concept, the researchers in this study created one. All the survey questions were developed based on the available literature in the subject matter e.g. The Autism Parenting Stress Index (APSI) and the World Health Organizations Quality of Life Questionnaire with Parents of Children with Autistic Disorder (34, 35). The survey questions were not contrived directly from these questionnaires, they were rather used as a guide as to how to design our survey and which questions to ask. The questionnaire was pilot tested first on a sample of three parents of autistic children to assess the studys measures for reliability, and to establish validity before embarking on the full study. Parents were asked to evaluate appropriateness of response options, time taken to complete it, and clarity of the questions in terms of language, wording, and meaning. Necessary corrections were considered and made by authors as appropriate. All measures and informed consent were then translated from English to Arabic by bilingual researchers in this study to enable families to complete forms in their preferred language [N=58 (21.4%) English, N=213 (78.6%) Arabic]. The final version of the questionnaire was comprised of 36 multiple-choice and open-ended questions about sociodemographic information, the impact of the pandemic on autistic childrens daily life, access to information and services/ support during the pandemic period, parents pandemic experience and primary challenges, and parents overall health status and stress levels.

Procedures

The preliminary version of the questionnaire was revised in an iterative process by three of the authors (FA, SA, and IG). All the researchers involved in data collection are Arabs fluent in both English and Arabic who have extensive experience in ASD research within the Arab community. The study employed two distinct recruitment methods. Initially, participants were reached through email, wherein they received a survey link. Families who chose to engage accessed, completed, and submitted the survey electronically. Alternatively, a second recruitment mode involved contacting families via phone. During this outreach, the studys purpose was explained, and families were given the option to either complete the survey over the phone with the researcher or independently. Consent was obtained electronically through an online form in all instances. Notably, this approach was particularly relevant given the studys timeframe coinciding with social distancing measures and the closure of centers, schools, and clinics. The survey took approximately 10- 15 minutes to fill out. If a parent had more than one autistic child, a separate survey was filled for each child. The survey pertained to the COVID-19 pandemic, and more specifically, the period of confinement and physical distancing in 2020.

Data analysis

The final raw data were downloaded from Google Forms into a Microsoft Excel file for analysis using SPSS software (Version 26.0). For the quantitative data, descriptive statistics were used to characterize the sample and examine survey responses. Then, chi square and likelihood ratio tests were used to investigate the association between parents stress levels and employment status, access to in-home therapy, access to any sort of specialized intervention, presence of hired help in the home (e.g., housekeeper, nanny, etc.), and regression in child skills. In order to identify the challenges that parents with autistic children face during the pandemic, the qualitative data collected by written responses through semi-structured forms was analyzed using thematic content analysis technique by identifying themes and subthemes and associating them with examples (36). Three authors (FA, SA, and IG) independently evaluated responses and placed them into categories (e.g., social isolation, mental and psychological problems, financial issues, access to regular support, service interruption, etc.). In the rare instances of discrepant category attribution, the authors reached consensus through discussion.

Results

Sociodemographic information

Parents provided basic sociodemographic information about themselves and their autistic child, including parent gender, nationality, and work status, as well as child age, gender, and diagnoses, along with the number of children at home and membership in ASD advocacy/family support networks. The majority of the participants were female (mothers; 66.4%), and non-Qatari (59.4%). Almost all fathers (90.4%) were employed, while most mothers (53.9%) were unemployed. The majority of parents do not work from home (64.9%) and are members of ASD advocacy and family support networks (67.2%). An average of four children lived at the home, including autistic children. The vast majority of autistic children were male (79.0%; n=214) with most (62.7%) falling between the ages of 9 and 13. Approximately one-third (31.0%) of the children had co-occurring conditions such as ADHD or epilepsy (see Table 1 for more details). To ensure a comprehensive understanding of each participants current level of functioning, our survey questions were occasionally supplemented with sub-questions. Some questions offered multiple options for selection, followed by inquiries about the presence of comorbid conditions, utilizing a yes/no format. Participants selecting “yes” were then prompted to specify the particular condition. Notably, information regarding the childs verbal ability was not explicitly addressed in a dedicated question; instead, it relied on data reported in the comorbid conditions or additional comments sections of relevant survey questions.

Survey responses: quantitative analyses of survey results

Impact of COVID-19 on autistic children and their families

Parent survey responses indicated that the COVID-19 pandemic has had a significant on autistic children in Qatar. As seen in Table 2, the majority of parents reported that their childrens sleeping schedules had been disrupted or changed since the start of home quarantine (69.4%). Most reported that their children displayed new problem behaviors (52.8%), such as hyperactivity, tantrums, self-injurious behavior, new stereotyped behaviors, and/ or disrupted sleep. Most parents also endorsed a noticeable regression in their childrens previously gained skills (54.2%), such as difficulty following instructions, reduced self-help skills, worsening social skills, increased attention issues, and/or reductions in communication and academic skills. Furthermore, most parents (64.6%) attributed specific problems/issues to the challenges of being home all day (e.g., boredom, aggression, mood/irritability issues, etc.). However, the vast majority of

TABLE 1 Sociodemographic information of autistic children and their parents.

Variable	N (Total N=271)	%
Parent gender		
Female	187	69.0%
Parent nationality (Qatari v. Non-Qatari)		
Qatari	110	40.6%
Parental employment status		
Employed fathers	245	90.4%
Employed mothers	125	46.1%
Employed parent currently working from home	95	35.1%
Member of ASD advocacy/ support group	182	67.2%
Child gender		
Male	214	79.0%
Child age range		
3 to 8	81	29.9%
9 to 13	170	62.7%
14 to 18	12	4.4%
above 18	8	3.0%
Child ASD diagnosis		
ASD	260	95.9%
ASD: High Functioning	4	1.5%
ASD and Down syndrome	4	1.5%
ASD: Nonverbal	3	1.1%
Child co-occurring conditions present	84	31.0%

parents (73.1%) indicated that their children were still participating in physical activities, either inside or outside the home. The COVID-19 pandemic was also found to have a significant impact on the daily lives of families in this study. The vast majority of parents (97.0%) reported that COVID-19 caused substantial changes in their daily routine, reduced social contact (96.7%), and increased their stress levels (58.7%).

Chi square tests were then used to assess the relationship between parental stress levels and key variables of interest, including: parent employment status, access to in-home therapy, access to any sort of specialized intervention, presence of hired help in the home (e.g., housekeeper, nanny, etc.), and regression in child skills. Findings indicated that from the predicted variables (Table 3), parent stress was significantly associated only with a regression in the childs previously gained skills, such that child skill regression was associated with increased parental stress [χ^2 (4, N=271) = 12.580, *p*=.014), such that child regression increased the likelihood of high parental stress thirteen-fold (Likelihood Ratio=13.127).

TABLE 2 Impact of COVID-19 autistic children and their families.

Survey Question	Yes (N)	% Yes
Is your child practicing any physical activity inside the home or outdoors?	198	73.1%
Did your childs sleeping schedule change since the start of the home quarantine/physical distancing measures?	188	69.4%
Did your child exhibit any negative behaviors since the start of the home quarantine/physical distancing measures?	143	52.8%
Did you face any problems/issues with your child being at home all day?	175	64.6%
Since the start of the home quarantine/physical distancing measures, did you notice any regression in your childs previously gained skills?	147	54.2%
Has your family been reducing social contact as a result of COVID19?	262	96.7%
Has COVID-19 led to significant changes in your familys daily routine?	263	97.0%
Survey Question	N	%
On a scale of 1-5, how would you rate your stress level during this time:		
Not stressed at all	16	5.9%
Normal level of stress	50	18.5%
Neutral	46	17.0%
Stressed	85	31.4%
Very stressed	74	27.3%

Impact of COVID-19 on *accessing* and *receiving* *services/support*

As shown in Table 4, the majority of parents in this study stated that they had difficulty receiving support from extended families/ friends/community during the pandemic (57.6%), that they could not access usual support due to COVID-19 (63.1%), that they were only partially or not at all supported by their families and community (55%), and that they did not have access to any online ASD support (e.g. family support groups, therapeutic

TABLE 3 Summary results of Chi square and likelihood ratio tests of predictors with parent stress level.

Variable	Pearsons χ^2	Likelihood Ratio
Father employment status	1.441 (4, N=271; *p*=.837)	1.501
Mother employment status	4.858 (4, N=271; *p*=.302)	4.903
Child receiving in-home therapy	11.972 (4, N=271; *p*=.152)	14.446
Child receiving any specialized intervention	7.905 (4, N=271; *p*=.443)	7.720
Presence of hired help in the home	11.522 (4, N=271; *p*=.485)	11.236
Regression in child skills.	12.580 (4, N=271; *p*=.014)	13.127

TABLE 4 The impact of COVID-19 on accessing and receiving services/support.

Survey Question	Yes (N)	% Yes
Did you find difficulty receiving support from your extended family/friends/community during this time?	156	57.6%
Is your autistic child presently participating in online learning?	112	41.3%
Is your child receiving any intervention sessions from a qualified specialist during the period of the home quarantine/ physical distancing measures?	65	24.0%
Does your family presently have access to any online ASD support (e.g., family support groups, therapeutic support, etc.)?	99	36.5%
Is there any type of support that your family usually receives but cannot access in the meantime because of COVID-19?	171	63.1%
Survey Question	**N**	**%**
On a scale of 1-4, how supported do you feel, whether from other family members, the community, etc.		
Not supported at all	65	24.0%
Slightly supported	84	31.0%
Supported	76	28.0%
Very supported	46	17.0%

TABLE 5 The main challenges families face during the pandemic.

Theme	Subthemes	*n*	Quotations
1. Social isolation	Abrupt Social Change and social anxiety Restricted all social outing and interaction Total	15 20 35 (13.5%)	*" The mandatory home quarantine has protected my family; however, it has also caused isolation and social anxiety in my autistic son."* *"Social isolation was difficult for the whole family."* *"City closure and quarantine restricted or diminished all social outings and opportunities for children to go out, interact, exert energy."* *"The social isolation affected us all negatively as a family."*
2. Mental health/ psychological problems	Anxiety Depression Family Stress Fear of getting the virus Health and psychological impact on children Feeling negative Total	10 5 10 30 10 3 68 (26.3%)	*"I became anxious about cleanliness, not seeing our families."* *"Fear of regression and integrating back into society and social life after quarantine."* *"Being at home all day with the kids was difficult for me … and them."* *"The pandemic has added more stress to an already stressful situation. Autistic children have daily routines when that routine is disrupted it has a mental and physical effect on the families and on the autistic child. … We have been lockdown since March no one has bothered to ask the already struggling familys how to cope with the lockdown."* *"The online learning is a struggle, and the interruption of all additional therapies that were supporting my sons progress has caused a real stress and regression on our family and on his skills."* *"Interruption of therapy and negative effect on my child, and caused high stress in our home."* *"My wife and I are both frontline healthcare workers, this has made it very difficult physically and psychologically straining and caused anxiety as we were worried that we would bring the virus home or catch the virus and then we would have to be quarantined away from our child. This is especially difficult for expat families who have no one here."* *"Emotional and psychological effects of the quarantine (depression, anxiety, fear for catching the virus), fear that the autistic child contracts the virus, how he would be able to handle self-quarantine (it*

(Continued)

support) (63.5%). Most also reported that their autistic children were not participating in online learning (58.7%) and did not receive any intervention sessions from a qualified specialist during the home quarantine period (76.0%).

Qualitative analyses: the main challenges families face during the pandemic

Parents opinions regarding the main challenges they faced during the pandemic were analyzed with thematic content analysis (Table 5). The main challenges that parents face during the pandemic are grouped under social isolation, mental health/ psychological problems, access to regular support, service interruption, financial, and job challenges, increase in childs negative behaviors and skill regression, outdoor activities, and learning/education challenges. The highest frequency is in the mental health/psychological problems, increase in childs negative behaviors and skills regression categories, social isolation, and lack of outdoor activities. The lowest frequency is in the Financial and job challenges category. The sub-categories with the highest frequency are regression in gained skills (*n* =56), fear of getting the virus (*n* =30), lack of outdoor activities (*n* =20) and restricted all social outings and interaction (*n* = 20).

Discussion

This study used parent report surveys to gain insight into the impacts of the COVID-19 pandemic on the lives of autistic children and their families in the State of Qatar. As expected, parents

TABLE 5 Continued

Theme	Subthemes	*n*	Quotations
			would be impossible).” *“Scared my kid would get the virus, who would take care of him if I had COVID: I am a single Mom and dont have family here.”* *“Fear of getting the virus and fear that if mother or father get the virus, who would take care of the autistic child during the time of quarantine or probable serious health complications.”* *“This epidemic has negative effects on the students psyche. Children with special needs do not understand quarantine and not go out, do not like to sit at home. The school was an outlet for them.”* *“The usual stress out because we cant see family and scared for them.”* *“Restricted movement and mental stress.”* *“My child and wife went to Egypt before the COVID-19 spread in Qatar, they couldnt return and now he had to be registered in a center in Egypt while they wait for the return, and it is not safe there in terms of prevention measures, and also my sons condition is much worse now because of this big change. This time has been very challenging for us.”* *“Job stress, interruption of everything”* *“Paralyzed our life and put us in really threatening issues”*
3. Accessing to regular support	Restricted Access to Therapeutic support and medical care Loss of support from the center and family Total	4 12 16 (6.2%)	*“Difficulty accessing Therapeutic support, medical care when we needed, and overall support from friends and community as we had been quarantined.”* *“Doctors appointments stopped, and we didnt know when they will return.”* *“Loss of support from the center and family”.*
4. Services interruption	Change in family daily routine and activities Interruption of intervention services Total	*12* 20 22 (8.5%)	*“ The interruption and complete change of our daily activities and routines this period has affected our childs progress very negatively Overall got worse in everything”.* *“Everything in the ASD service provision is profit based, everything is expensive, everything is a “show”, it is so hard to find quality intervention, the change in the daily routine*

(Continued)

TABLE 5 Continued

Theme	Subthemes	*n*	Quotations
			affected my child greatly” *“There was a definite negative effect from the stop of intervention”* *“The interruption of all activities and therapies that I was doing for my child to develop her social and communication skills. the interruption of services and social gatherings to me is considered the most negative aspect of COVID-19 time”.*
5. Financial and job challenges	Financial strain Fear for job loss add stressors Total	5 6 11 (4.2%)	*“My wife lost her job during this time, so this was one of the added stresses for us as a family, the financial strain and fear for job loss for me as well. this was definitely a stressful time for everyone”.* *“All life and daily routine changes associated with the quarantine and how COVID-19 affected our lives was a challenge and continues to be a challenge. Fear for job loss is also a challenge”.* *“Worry about if our son worsens (due to the social isolation) and also the stress due to the financial impact of COVID-19 on all jobs in the country”.* *“All measures taken were in our favor to protect our families and residents in Qatar. The only negative aspects are the financial strains and stress from fear job loss as this has affected the economy”.*
6. Increase in childs negative behaviors and skills regression	Regression in gained skills Behavioral challenges Total	56 10 66 (25.5%)	*“Challenge to convince a child of why they cant go out, left alone a child with communication issues. Intervention stopped and child regressed.”* *“Fear of child regressing.”* *“It was a big struggle for me not being able to deal with my childs behavior and feeling that I cant help continuing the intervention at home.”* *“Regression in skills due to stop of intervention, trying to give them useful activities to do, stress, social isolation, lack of leisure activities.”* *“Communication and behavioral regression in my child as a result of being home all day and stopping of intervention, social isolation, lack of leisure or extracurricular activities.”*

(Continued)

TABLE 5 Continued

Theme	Subthemes	n	Quotations
7. Outdoor activities	Lack of outdoor and leisure activities Travelling restriction Total	20 7 27 (10.4%)	*"Lack of social outings, leisure activities, and social interaction due to the quarantine."* *"Closure of everything, no leisure activity, not even beaches or parks, everything was closed, it was hard, and we werent able to take him out to exert some energy."* *"Social isolation, not being able to travel"*
8. Learning/ Education challenges	Lack of trust on online learning School closure & regression in education Lack of educational programs for special needs and extracurricular Total	3 6 5 14 (5.4%)	*"The online learning is not working out for us. It is not enough for our child and this type of learning isnt for all learners".* *"Regression in education and daily skills"* *"Fear of lowering his school level".* *Stopped extracurricular activities, school closures, social isolation, etc"*

reported high levels of distress and disruption to their daily lives, as has been widely reported throughout the world. The majority of parents reported that their childrens access to activities, education, and treatment was either substantially reduced or non-existent. Parents also reported reduced access to family and social support networks during this critical time of increased stress. Interestingly, parental stress was not significantly associated with support factors, such as access to treatment and social support, nor was it associated with parental employment status. This is in direct contrast to prior studies of families caring for autistic children, which routinely find an association between familial stress and access to support services (29, 37). It is possible that families were under so much stress during this intense period of lockdown that even access to support provided minimal relief.

The data also indicate that families had minimal access to support and that available supports were routinely of lower quality than those provided before the COVID-19 pandemic; thus, the lack of association indicates that the services provided were insufficient to impact family stress levels. Parental stress was significantly associated with child developmental regression, indicating that children whose support needs increased even more during this time due to skill loss likely increased parental stress. Furthermore, the majority of parents indicated that their childrens sleeping habits had been interrupted or changed since the start of home quarantine, that their children had shown negative behaviors, and that there had been a clear regression in the childrens previously acquired abilities. Beyond the quantitative data collected in this study, the qualitative data analysis provides valuable additional insights into the unique experience of parenting an autistic child during the COVID-19 pandemic. While many of the experiences endorsed by parents in quantitative data were likely shared by parents of neuro-typical children (e.g., reduced access to activities, financial and employment stress, lack of connection to support networks) (38), the qualitative data reveal stressors and experiences unique to parents of autistic children (39). Throughout the major themes that emerged, two major underlying threads were clear that connected the stress expressed in each of the themes and subthemes.

Firstly, parents emphasized that they had already been under enormous stress with insufficient support to care for their children prior to the start of the COVID-19 pandemic and subsequent lockdowns. Parents indicated that services for ASD were already scarce and that there was little societal understanding and support for the challenges that they and their children faced before the pandemic. Parents in this study shared feeling "forgotten" by society, stating that because their needs were already overlooked and their children ignored before the COVID-19 pandemic, it felt clear to them that the unique impact of the pandemic on their children and families was not recognized or considered by society at large. Thus, while they reported concerns that are similar to those echoed by parents of neuro-typical children, these concerns emerged in the context of pre-existing distress and unmet support needs. The lockdown was often framed in their comments as a new layer of stress that felt "impossible" to handle on top of their pre-existing experiences.

Secondly, parents highlighted how their childs symptoms of ASD compounded the stressors of the COVID-19 pandemic lockdown experienced by all families. Although all families experienced stressful disruptions to their daily routines, parents in this study noted that their children relied intensively on predictable routines before the pandemic, even more so than their peers did, with even small changes having the potential to be highly disruptive. These families thus felt the catastrophic changes wrought by the COVID-19 pandemic even more intensely. Similarly, families around the world were negatively impacted by the lack of opportunities for social interaction for their children. The lack of social interaction was particularly worrisome to families in this study, as difficulties with social communication and engagement skills are a core feature of ASD, which are targeted directly in treatment and education for these children. Families expressed their worries that the social isolation of the pandemic would lead to further delays in their children and/or loss of skills. Concerns about regression, which occurs much more commonly in autistic children than in neuro-typical children, also emerged across themes. Parents highlighted that not only was their child failing to learn and gain new skills during this time, but also that there was a very real risk that their child might lose previously gained skills (and in some cases had already). In addition to developmental regression and skill loss, parents also shared that their children experienced exacerbations in pre-existing negative behaviors or developed new negative behaviors, as a unique expression of the impact of the lockdowns on autistic children.

Finally, their childrens underlying difficulties with learning and social attention attempted at online education and intervention, when available, extremely difficult, or even impossible to access. Since these learners require different types of instruction, they were often left with recommendations for instruction to be practiced by the families, rather than direct instruction. The online learning format substantially increased demands on both educators and families to support students learning around the world (24), with minimal time and resources to adapt special education curriculums to online learning with the unique needs of autistic students in mind.

An additional challenge not captured by the present survey is the delay in diagnosis and identification. In addition to the impact on treatment and educational services, diagnostic assessments have also been affected, causing delays in diagnosis for many individuals. This in turn can have severe negative long-term outcomes due to delays in access to treatments and appropriate interventions (9). Access to early diagnosis and intervention is a strong predictor of long-term outcomes (40, 41), meaning that children whose diagnosis and access to treatment are delayed during this time are at substantial risk for even more negative long-term outcomes with higher support needs.

Limitations

The current study also has some limitations. First, like many online research studies, our sample may reflect some degree of selection bias. In particular, we expect certain underestimations of extreme cases, that is, people who were either minimally or very affected by the pandemic. Second, the results of this study are limited to the immediate experience at the onset of the pandemic and, therefore, to the short-term effects of the pandemic. Future studies also need to consider the long-term effects of the pandemic as it is becoming increasingly clear that this pandemic and any future pandemic are likely to have a prolonged course. Thirdly, the study methodology and data exclusively involve input from parents/guardians, resulting in the absence of perspectives from autistic individuals themselves. This constitutes an additional limitation to the study that should be taken into account in future research.

Conclusions

The COVID-19 pandemic and recurrent lockdowns have already had an enormous impact on our world, and their effects will be felt for years to come. As vaccinations continue to become more available and access to services and education steadily increase, we cannot simply "go back to normal." It will be critical for providers and educators to consider the effects of the ongoing pandemic on childrens development, academic progress, and emotional well-being. Moreover, the medical community should learn from this crisis and to support autistic families in navigating burdensome times to enable autistic children to thrive. As evidenced by the high levels of distress described by parents in this study, the development of personalized formulation-based-psycho-social interventions to support and engage autistic individuals and their caregivers to help cope with the consequences of the pandemic and similar waves in the future is critical (20). As highlighted in this study, there have been substantial disruptions to the lives and developmental progress of autistic children. These disruptions will have lasting effects on their skills, including potential skill loss. Adjustments will need to be made to educational, treatment planning that adjust developmental, and educational goals to remediate skills and begin helping children catch up on lost time. The emotional impacts of this time will also need to be considered, including that many children may have had a traumatic reaction to the disruptions in their routines and lives. Trauma-informed approaches to both treatment and education are likely to have much more relevance in the field of ASD going forward than they have in the past.

There will be a pressing need for society to not only stop neglecting the needs of autistic children and their families but to begin actively supporting them in enhanced ways. Local and national governments will need to consider increased supportive initiatives for psychological support, financial support, training workshops, and online sessions for families and providers. This should also include additional support and incentives for provider and teacher training in ASD. The interruption of service provision whether home-, school-, or center-based, by experienced and highly skilled multi-disciplinary professionals is expected to have a negative effect on these service providers as they have acquired their skills and continue to enhance them through their daily practices while working with autistic individuals. This has also limited opportunities for trainees to develop critical skills needed for working in ASD. Reduced training opportunities will in turn mean fewer qualified providers are available, in a system that is already unable to fully meet the needs of autistic children. Increasing access to services through support to providers will also be critical. Moving forward into the "new normal," governments around the world will need to make substantial and lasting investments in training, family support, education, and services for this vulnerable group of children and their families. The greater impact of the pandemic on the autistic children and their families emphasizes the need for accessible and affordable (continued) health, education, and family services to manage their special and immediate needs.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material. Further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Qatar Biomedical Research Institute - Institutional Review Board (IRB). The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants legal guardians/next of kin. The parents/legal guardians of the adult participants provided written informed consent as they are usually the ones who provide consent on their behalf.

Author contributions

FA: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Writing – original draft, Writing – review & editing. IG: Data curation, Methodology, Project administration, Writing – original draft, Writing – review & editing. SA-H: Conceptualization, Formal analysis, Funding acquisition, Writing – review & editing. ML: Conceptualization, Investigation, Methodology, Writing – review & editing. HA-S: Data curation, Investigation, Writing – review & editing. FA-F: Data curation, Writing – original draft, Writing – review & editing. IT: Data curation, Formal analysis, Writing – review & editing. AR: Data curation, Formal analysis, Writing – review & editing. AN: Writing – review & editing. MT: Conceptualization, Investigation, Resources, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2024.1322011/full#supplementary-material

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Relationship of autistic traits and the severity of fear of the COVID-19 pandemic in the general population

Dominika Bieczek[1]*, Adrianna Ściślicka[1], Agnieszka Bobowska[1], Filip Tomsia[1], Krzysztof Maria Wilczyński[2,3] and Małgorzata Janas-Kozik[2,3]

[1]Students' Scientific Society, Department of Psychiatry and Psychotherapy of Developmental Age, Medical University of Silesia, Katowice, Poland, [2]Department of Psychiatry and Psychotherapy of Developmental Age, Medical University of Silesia, Katowice, Poland, [3]Department of Psychiatry and Psychotherapy of Developmental Age, John Paul's II Pediatric Center, Sosnowiec, Poland

Background: The aim of the study was to investigate the level of fear of the COVID-19 pandemic and to detect a possible correlation between the autistic traits and the level of fear and to learn about other factors that may affect the level of fear.

Methods: The study utilised a questionnaire and was conducted online in the period from 16.02.2021 to 11.06.2021. The test group consisted of 214 respondents with an average age of 23.78 years (95%CI: 22.48 – 25.08; max: 61, min: 14) from the general population. The study used The Autism-Spectrum Quotient (AQ) questionnaire to assess the degree of autistic traits in the general population and The Fear of COVID-19 Scale, which was used to assess the level of fear of COVID-19.

Results: Among the respondents, 9 people scored $\geq$32 on the AQ test and were considered to have a high degree of autistic traits. In multiple regression ($R^2 = 0.1$, $p<0.0001$), a positive relationship between the severity of fear of COVID-19 and the autistic traits ($p=0.01$) and age ($p<0.001$) was obtained. Additionally, a second multiple regression ($R^2 = 0.1$, $p<0.000001$) including the subscales of AQ was performed and a positive relationship between the severity of fear of COVID-19 and the difficulties in attention switching ($p=0.0004$) and age ($p=0.00001$) was obtained.

Conclusion: People with higher autistic traits present greater fear of the COVID-19 pandemic. We suggest that it might be caused by cognitive stiffness and disorders in emotions regulation, according to the literature. The elderly also present higher levels of fear. The other variables did not affect the level of fear of the COVID-19 pandemic.

KEYWORDS

autism spectrum disorder (ASD), fear, COVID-19, autistic traits, attention switching

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EDITED BY
Michaela DuBay,
University of Virginia, United States

REVIEWED BY
Cecilia Montiel Nava,
The University of Texas Rio Grande Valley,
United States
Makoto Wada,
National Rehabilitation Center for Persons
with Disabilities, Japan

*CORRESPONDENCE
Dominika Bieczek
dominikabieczek@wp.pl

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Background

The emergence of COVID-19 infections in 2019 in the city of Wuhan began a cycle of huge changes in our daily lives, their effects are visible in all areas – from private to professional life. The dynamic changes of the situation contributed to the announcement of the COVID-19 pandemic by the World Health Organization (WHO) on 11 March 2020 (1). The hitherto unknown virus quickly began to spread around the world, leading to the establishment of epidemic states in most countries of the world. The global health system faced the enormous challenge of preventing the spread of the pathogen and introducing an effective defence strategy (2).

Unfortunately, the pace of spreading the pandemic and the wide range of clinical symptoms ranging from asymptomatic to severe acute respiratory syndromes and multi-organ disorders have had a negative impact not only on physical health (3). The implemented methods to prevent the spread of SARS-CoV-2, including, among others, mass school and workplace closing, have disrupted everyday functioning and changed the concept of a normal lifestyle. The sudden need for social isolation, worrying about one's own health and safety, and growing unemployment as a result of the introduced restrictions have led to the mental imbalance of many people (4). An increase in the occurrence of dysfunctional behaviours, emotional stress, defensive reactions such as aggression, fear, anxiety, frustration, depression and suicidal tendencies was observed (5). It has been shown that the severity of emerging mental health disorders may vary depending on the studied population. Older people (6), children (7) or health care workers (8) may report varying levels of severity of the disorders. Particularly noteworthy are psychiatric patients, whose level of anxiety may be multiplied as a result of incorrect interpretation, for example, of media coverage. People with autism spectrum disorder; (ASD) present problems in the field of selected cognitive functions, among others, speed of information processing, verbal memory, reasoning or problem solving, as well as interpreting the information that they reach (9). Sensationally charged information about COVID-19 in the mass media could significantly hinder adjusting the subjective sense of threat to its actual degree by people with ASD.

Since the beginning of the COVID-19 pandemic, there have been many articles published that have described the experiences of people with various neurodevelopmental disorders with the regulation of emotions in response to stressful stimuli. The authors drew attention to the problems arising from the loss of routine due to the introduction of new regulations aimed at avoiding the spread of infection (10). In addition, patients with neurodevelopmental disorders have a higher risk of developing mental illnesses. Already at the very beginning of the pandemic, parents of children with neurodevelopmental disorders reported increased anxiety and increasing mental problems of their children (11). Studies conducted so far have shown a higher level of anxiety related to the COVID-19 pandemic in people with neurodevelopmental disorders compared to the general population (10, 12). Loss of routine was a strong predictor of increased anxiety in people with ASD (12, 13).

The basic features of ASD are persistent difficulties in social communication, establishing and maintaining relationships and the occurrence of repetitive and stereotyped patterns of interests and activities (14). The functioning of autistic people in terms of social development can be very diverse. Impeded social interactions are manifested by difficulties in non-verbal communication and development of peer relationships. They are also characterised by difficulties engaging in emotional reciprocity and difficulties with sharing a common field of attention by sharing joys, interests, or achievements with other people (15). Autistic people feel threatened when their environment changes, as they have varying degrees of adaptability (16). Autistic people tend to misregulate their emotions by using maladaptive strategies, such as isolation, information avoidance or excessively searching for information, rumination, suppression of expression of emotions, aggressive or repetitive behaviours. Better strategies are sharing one's thoughts about stressful situations and distraction that is connected with shifting one's attention to something else in order to avoid unwanted emotions. The best strategies are cognitive reappraisal, focusing on the positive and humour (12).

Another important issue is the prevalence in the population of a constellation of subclinical features of autism spectrum disorder known as the Broad Autism Phenotype; (BAP). Autism is a continuum of various symptoms that are present in the general population. Everyone has different levels of these features. In between the dichotomous division between the population that has received a diagnosis and the population that does not have enough traits to get one, there are people who present only few traits. As an example of such people is the phenomenon of BAP that was initially analysed in the context of siblings of people with ASD (17, 18), but currently there are general population analyses available in the literature, which determine the frequency of BAP at 9 (19) to even 25% (20) of the population. People from the BAP group present the features of ASD primarily related to the area of social cognition disorders, among others, in the interpretation of facial expressions or theory of mind (21, 22).

Difficulties in adapting to changes raise the question of whether the autistic traits had an impact on the level of fear of the COVID-19 pandemic. For example, a study of the reactions of people injured after the earthquake in L'Aquila in Italy showed that people with higher autistic traits tended to have an inadequate assessment of the situation and denied the need for emotional support (23). In addition, ASD is often accompanied by alexithymia, which intensifies difficulties with the interpretation of internal feelings and with their proper reception and expression (24). Autistic people tend to use patterns to avoid emotional stimulation and to suppress emotions instead of analysing and evaluating them adequately. This may be related to difficulties in coping with experienced emotions and an issue in realising the cause of one's feelings (25). In turn, increased cognitive rigidity in autistic people predisposes to a literal interpretation of incoming information and adaptation problems. The pandemic situation has forced a change in lifestyle and social behaviour and staying at home, in a familiar environment. During

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Abbreviations: WHO, World Health Organization; ASD, autism spectrum disorder; BAP, Broad Autism Phenotype; AQ, The Autism Spectrum Quotient; FCV-19S, The Fear of COVID-19 Scale.

the survey, the surveyed population must obey the sanitary regime, including: in cultural facilities such as museums, cinemas and theatres, it was possible to occupy a maximum of 50% of the seats, there was also an obligation to wear masks, in hotels it was possible to accommodate a maximum of 50% of the rooms, restaurants served only takeaway meals, water parks and gyms remained closed. The reaction of autistic people could differ from the reaction of the general population.

The aim of the present study was to determine the relationship between the severity of fear of the COVID-19 pandemic and the autistic traits in the group of participants from the general population from Poland. It also took into account the effect of individual traits of ASD, such as social skills, communication, imagination, attention to detail, attention switching/tolerance to changes, on the severity of fear.

Methods

Participants

The study population included adolescents and adults (the youngest participant was 14 and the oldest was 61) residing in Poland at the time of the study - 16.02.2021-11.06.2021. Of the people tested, 128 (59.81%) were women, 78 (36.44%) were men, and 8 (3.75%) people preferred not to give information about sex. Of the group of people with AQ>32, 3 (33.33%) were female, 5 (55.55%) male, and 1 (11.11%) person preferred not to give information about one's sex. On the other hand, in those with AQ <32, 125 (60.98%) were women, 73 (35.61%) were men, and 7 (3.41%) preferred not to give information about one's sex. The mean age in the study population was 23.78 (95%CI: 22.48-25.08). The mean age in the AQ>32 group was 18.89 (95%CI: 15.03-22.74) and in the AQ<32 group was 23.99 (95%CI: 22.66-25.33) years.

In the studied group, 56 people had primary education (26.19%), 18 people had lower secondary education (8.41%), basic vocational education – 4 people (1.87%), secondary education – 36 people (16.82%), higher education – 49 people (22.9%), and 51 people were students (23.83%). In the context of the place of residence, 27 people indicated villages (12.61%), 38 people cities up to 50 thousand inhabitants (17.75%), 28 lived in cities up to 100 thousand inhabitants (13.08%), in cities up to 250 thousand inhabitants - 49 people (22.89%), and in cities >250 thousand inhabitants - 72 people (33.64%). The demographic analysis is presented in Table 1.

Among all of the participants, 30 (14.02%) people were infected with SARS-CoV-2 at the moment of the questionnaire or before, and 184 (85.98%) were never affected by the disease. When it comes to people with AQ ≥32, 2 (22.22%) people had COVID-19.

TABLE 1 Demographic analysis of the study population.

	Study group	AQ >32
Female	128 (59.81%)	3 (33.33%)
Male	78 (36.44%)	5 (55.55%)
Preferred not to give information about sex	8 (3.75%)	1 (11.11%)
Mean age	23.78	18.89
Education		
Primary education	56 (26.19%)	5 (55.55%)
Lower secondary education	18 (8.41%)	1 (11.11%)
Basic vocational education	4 (1.87%)	0
Secondary education	36 (16.82%)	0
Higher education	49 (22.9%)	0
Students	51 (23.83%)	1 (11.11%)
Population density		
Living in villages	27 (12.61%)	0
Living in cities up to 50 thousand inhabitants	38 (17.75%)	0
Living in cities up to 100 thousand inhabitants	28 (13.08%)	1 (11.11%)
Living in cities up to 250 thousand inhabitants	49 (22.89%)	1 (11.11%)
Living in cities >250 thousand inhabitants	72 (33.64%)	5 (55.55%)
Infection with SARS-CoV-2	30 (14.02%)	2 (22.22%)

Materials

The presented paper uses the Polish version of The Autism Spectrum Quotient (AQ) questionnaire, which quantifies the traits of autism (26) and the Polish version of The Fear of COVID-19 Scale (FCV-19S) questionnaire, which quantifies the severity of COVID-19 fear (27).

The Autism Spectrum Quotient has been translated and validated in the Polish population (28). It contains 5 theoretically defined subscales examining individual autistic behaviours: communication, imagination, social skills, attention switching and attention to detail. It consists of 50 questions, 10 questions for each subscale. The original cut-off point is 32 points (29).

The Fear of COVID-19 Scale has also been translated and validated in the Polish population (30). This is a short questionnaire developed at the beginning of the pandemic. It assesses emotional responses to COVID-19. It contains 7 questions, each of which is scored from 1 to 5. A score of ≥27 is defined as a high level of fear, a score of ≥20 means a moderate level of fear, a score of ≥9 means a low level of fear, a score of <9 means no association between fear and COVID-19.

Procedures

The study was conducted between 16.02.2021 and 11.06.2021. The presented study was conducted in the form of an online questionnaire and was available via the Internet, for example, on social media websites (primarily facebook.com and instagram.com).

The inclusion criteria was age more than 13, because the version of the AQ used in this study is validated only for people of age 14 and older. Moreover, the questionnaire must have been properly filled. The exclusion criteria was only an improperly filled questionnaire.

It included 214 people with an average age of 23.78 years (95% CI: 22.48 – 25.08; max: 61, min: 14). The mean AQ score in the group was 18.65 (95%CI: 17.71 – 19.6; max: 41 min: 5). The group of people with an AQ score <32 was 205 people (95.8%), while 9 people achieved an AQ score of ≥32, which corresponds to about 4.2% of the study population.

In addition, an analysis of the distribution of AQ, FCV-19S and age was performed. The Kolmogorov-Smirnov and Lillefors tests showed no statistically significant differences between the normal distribution and those observed with p=0.05 for the AQ and FCV-19S results. These types of differences were observed for the age of respondents. The distribution of AQ in the study population is present in Figure 1.

In the statistical calculations, StatSoft Statistica version 13 software was used. The assumed level of statistical significance was α=0.05. The Spearman correlation was used to establish the relationship between AQ values x FCV-19S score, AQ subclasses x the severity of fear, age of participants x FCV-19S, education x FCV-19S, place of living x FCV-19S, a positive history of COVID-19 x FCV-19S and age of participants x AQ values. The Mann-Whitney U test was used to test the relationship between sex and FCV-19S. Multiple regression was performed using the backward stepping method. The dependent variable in both regression models was FCV-19S score and the predictors in the first regression model were AQ, age, place of living, education, SARS-Cov-2 infection in the past and sex. In the second one the dependent variables were AQ attention switching, age, AQ communication, AQ imagination, AQ social skills, AQ attention to details, sex, place of living, education and SARS CoV-2 infection in the past.

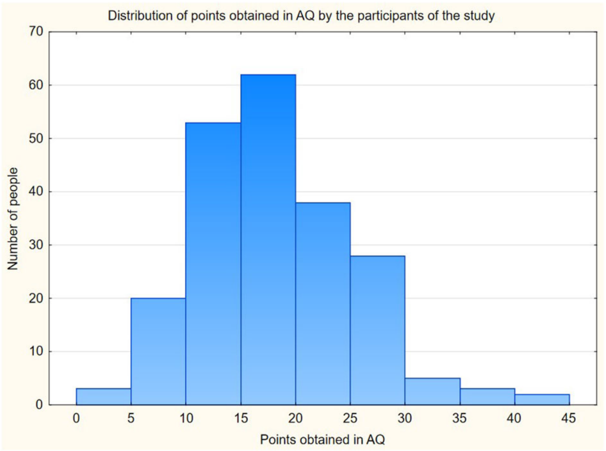

FIGURE 1
The distribution of points obtained in AQ by the participants of the study. Legend: The axis x presents points obtained in the Autism Questionnaire by the participants of the study. The axis y presents the number of people who obtained these points.

Results

For the total sample, the fear of COVID-19 was in a moderate range (x=13.41, SD=4.9, min: 7, max: 30). A weak relationship between autistic traits and the level of fear of COVID-19 was presented in the Spearman correlation (r=0.16; p=0.01).

In addition, the analysis of the relationship between individual autistic traits and the severity of fear using the Spearman correlation showed a weak relationship between difficulties in switching attention and the severity of fear of COVID-19 (r=0.16, p=0.02). The results of the analysis of the relationship between the rest of individual autistic traits and the severity of fear using the Spearman correlation showed no relationship: between difficulties in communication and the level of fear of COVID-19 (r=0.03, p>0.05), between difficulties with imagination and the severity of fear of COVID-19 (r=-0.07, p>0.05), between problems with social skills and the intensity of fear of COVID-19 (r=0.06, p>0.05) and between troubles with attention to details and the severity of fear of COVID-19 (r=0.05, p>0.05).

In addition, the severity of fear of COVID-19 was analysed depending on other factors. First, the relationship between sex and the severity of fear of COVID-19 was analysed, showing statistically significant differences in the Mann-Whitney U test (p=0.00). The analysis excluded people who preferred not to give information about sex. The mean level of fear of COVID-19 for women was 14.2 (95%CI: 13.35 – 15.05; SD: 4.87) and for men 11.98 (95%CI: 10.93 – 13.04; SD: 4.67). Next, a correlation analysis between the level of fear of COVID-19 and age was performed using the Spearman rho test, obtaining a weak relationship between the analysed parameters (rho=0.15; p<0.05). Subsequently, the relationships with education (rho=0.03, p>0.05), place of living (rho=-0.06, p=0.42) and a positive history of COVID-19 (rho=-0.07, p>0.05) were also analysed, obtaining statistically nonsignificant differences and dependencies between the examined parameters. Moreover, we analysed the relationship between age and autistic traits using the Spearman rho test and found no statistically significant correlation (rho=-0.06, p=0.35).

Multiple regression analysis was also performed using the backward stepping method with the assumed significance level of α=0.05.

A normality analysis of the residuals was performed using the Kolmogorov-Smirnov test with the Lillefors correction, obtaining p=0.09, confirming the assumption that they are subject to normal distribution. The model included the AQ score and the age of the respondents and was statistically significant. The parameters of the model were equal to R^2 = 0.1 (F=11.5; p<0.0001). The complete model is presented in Table 2. In the analysis of all variables – without the stepwise method – the statistical significance at α=0.1 was also used by the parameter "sex" with a low, negative parameter ß=-0.12.

A second multiple regression analysis was also performed using the backward stepping method with the assumed significance level of α=0.05. The model included the subclasses of AQ score and the age of the respondents. The model was statistically significant. The parameters of the model were equal to R^2 = 0.1 (F=14.73;

TABLE 2 Multiple regression regarding factors influencing the severity of fear according to FCV-19S test results.

Independent variables	b	std. err of b	t (207)	p
Constant	10.88	2.69	4.04	0.00008
AQ	**0.12**	**0.05**	**2.53**	**0.01**
Age	**0.15**	**0.04**	**3.91**	**<0.001**
Place of living	-0.19	0.23	-0.86	0.39
Education	-0.19	0.19	-0.99	0.32
SARS-CoV-2 infection in past	-0.21	0.94	-0.22	0.83
Sex	-1.06	0.58	-1.83	0.07

The bold values mean that they are statistically significant.

$p<0.000001$). The model showed the influence of AQ attention switching ($p=0.0004$) and age ($p=0.00001$) on the level of felt fear of COVID-19. The complete model of this regression analysis is presented in Table 3.

Discussion

The aim of the present study was to determine the relationship between the severity of fear of the COVID-19 pandemic and the autistic traits in the group of participants from the general population from Poland. It also took into account the effect of the individual traits of ASD, such as social skills, communication, imagination, attention to detail, attention switching/tolerance to changes, on the severity of fear.

Since autistic traits are continuum, even for the people from the general population without the diagnosis of ASD, the higher the level of autistic traits they have, the higher the likelihood of difficulties characteristic for ASD is. ASD characteristic's feature is increased cognitive stiffness and difficulties in relating the information obtained to the context. Media reports on COVID-19, charged with a large dose of sensation, in the perspective of this type of cognitive deficits, are material difficult to clear from the emotional load. For this reason, people with ASD may have difficulty processing information on this subject, which in turn may lead to incorrect reconciliation of the level of fear with the actual level of threat, which will significantly influence the functioning. In fact, the study population showed an effect of the difficulties with attention switching (one of the autistic traits) on the degree of fear of the COVID-19 pandemic. Of course, the obtained regression parameters indicate a small impact, which suggests that this is one of many factors determining the response to such threats. The psychological response to stimuli that induce high levels of stress is conditioned by many different factors. Functional disorders can take the form of chronic stress, delayed reaction to stress that decreases over time or resistance to stress. An individual's emotional response to stress is largely determined by perceived or actual exposure to stress, but also by a person's internal resources and external resources. Factors conducive to resistance to the perceived high level of fear, anxiety and stress include optimism, social support, the ability to critically assess the media message, reducing the feeling of social isolation, especially through online communication during the pandemic. At the level of family relationships, adaptability, family cohesion, good communication and proper financial management play an important role (31). A factor considered to have a particularly protective effect during stressful situations is having an external source of social support. Positive high-quality social support can increase resistance to stress,

TABLE 3 Multiple regression regarding factors influencing the severity of fear according to FCV-19S test results (with subclasses of AQ).

Independent variables	b	std. err of b	t (207)	p
Constant	10.8	2.75	3.92	0.0001
AQ attention switching	**0.46**	**0.17**	**2.75**	**0.006**
Age	**0.17**	**0.03**	**4.43**	**0.00002**
AQ communication	0.3	0.22	1.44	0.15
AQ imagination	-0.11	0.2	-0.54	0.59
AQ social skills	-0.05	0.17	-0.28	0.78
AQ attention to details	-0.11	0.15	-0.74	0.46
Sex	-0.86	0.58	-1.48	0.14
Place of living	-0.2	0.22	-0.88	0.38
Education	-0.26	0.19	-1.37	0.17
SARS-CoV-2 infection in past	-0.29	0.94	-0.31	0.76

The bold values mean that they are statistically significant.

help protect the development of trauma-related psychopathology and reduce the functional consequences of trauma-induced disorders (32). In contrast, strong predictors of trauma-induced disorders are a lack of social support, low intelligence and a lack of education, positive family history, previous psychiatric history, and aspects of the trauma response itself, such as dissociative responses (33). An important factor that increases the likelihood of developing a high level of stress is also the intensification of self-criticism and low self-esteem with insufficient ability to feel self-compassion, i.e. kindness towards oneself when experiencing disappointments and painful life experiences (34). Also, the history of traumas experienced so far and difficult life situations, especially those experienced during childhood, is not without significance. The brain is characterised by the greatest plasticity in childhood and adolescence. While it has many benefits, allowing children to learn quickly from experiences and adapt to the environment in which they are raised, it can also have long-term consequences for children raised in adverse conditions. In particular, environments characterised by violence and a high potential for harm can influence social, emotional and neurobiological development patterns in a way that enables the rapid detection of potential threats. Although these developmental adaptations may increase safety in hazardous environments by mobilising behavioural responses to avoid threats, they may also increase the risk of many forms of psychopathology (35).

According to the adopted hypothesis that the level of autistic traits have effect on the level of fear of the COVID-19 pandemic, the obtained results also indicate that difficulties with attention switching and connected with that difficulties with regulation of emotions are the areas that most strongly determine the subjective sense of fear in the face of danger in people with higher autistic traits scores. Parameters that are less important or do not affect level of fear are impaired ability to see a holistic picture of the situation, low awareness of the potential consequences, problems with social interaction, and communication. Similar results were also obtained in the studies of other authors. Hollock et al. (36) have shown that cognitive inflexibility can be an important factor associated with emotional difficulties. Thus, patients with higher levels of autistic traits who show greater cognitive stiffness than those with lower levels of autistic traits may experience co-occurrence of emotional and behavioural difficulties. The association of cognitive rigidity with level of fear may result from reduced tolerance of uncertainty, which has a documented association with anxiety and fear levels in children with ASD (37). Higher levels of fear can be associated with disturbances in the effective regulation of emotions as well. Ineffective coping mechanisms for a variety of emotional states in response to stress stimuli can lead to inappropriate behavioural responses in people with ASD. Insufficient innate ability to regulate emotions is also associated with deficits in the area of theory of mind, i.e. the ability to cognitively and affectively accept other people's perspectives and understand their intentions, as well as recognise their own state of mind (38). Regardless of this, according to literature data, patients with ASD experience all emotions, including anxiety, more strongly (39), hence they may have a higher severity of fear of the COVID-19 pandemic than in the general population. People with ASD suffer from difficulties in adapting to the changing environment around them (40), which in the face of sudden changes caused by the start of the pandemic may have exacerbated their fear. The ability to switch attention is a factor in reducing the level of anxiety and fear (41), while less effectiveness in its range predisposes to a higher level of anxiety and fear (42). Appropriate mindfulness and concentration exercises reduce the symptoms of anxiety while increasing the flexibility of attention (43).

For this reason, it is necessary to take care of the population of people with higher autistic traits by creating programs aimed at teaching concentration, attention and coping with stressful situations. Studies have found that people with higher levels of autistic traits are more sensitive to the psychosocial effects of the pandemic, such as anxiety, depression, financial problems, job loss or marital problems. Rapidly changing social and environmental conditions, such as the beginning of the COVID-19 pandemic, point to the need to increase access to psychological and psychiatric care. It is also important to note that developing mental health problems in people with higher autistic traits can increase the time to contact with healthcare and to receive optimal help. Health system management bodies must correctly recognise the complex problems of this group of patients and the psychological losses they suffer. The overriding goal should be to minimise and alleviate their discomfort, as well as to facilitate the return to the previous level of functioning in society. In order to better deal with these types of psychosocial problems affecting people with higher levels of autistic traits, the government and health professionals should create an appropriate model for intervention and prevention of psychosocial crises. The needs of people with higher degree or autistic traits or ASD are different from those of the general population, and health systems governing bodies should provide them with the support and appropriate care that could be crucial in the next peaks of pandemics, crises and disasters around the world. The law should guarantee additional freedoms for patients with ASD in crisis situations, but at the same time they should ensure their safety (44). Guidelines and recommendations for protecting the mental health of people with ASD in the face of a pandemic are well known in the scientific community (45), but they should also be disseminated in the general population, especially in health care facilities and among bodies responsible for setting up support programmes for people with higher autistic traits. It seems a good idea to replace face-to-face communication with online contact during periods of difficult social interaction, as well as training programs for relatives of ASD patients so that they can be able to provide patients with the necessary support to cope with stressful situations (46).

In the present study, there is an overrepresentation of people with higher autistic traits according to the results they obtained in AQ (≥32), whose percentage was equal to about 4.5% of respondents. This is more than four times higher than the estimated population frequency worldwide, which is about 1% (47). This difference is probably the result of the methodology used, i.e. a questionnaire survey conducted by social media. They allow reaching different groups of people through platforms that often suggest topics to the user and groups similar to your search history and interests. The forms provided by us were found not only on social profiles, but also on groups and websites devoted to the above-mentioned disorders. Because of this, the recipients of the questionnaire were people interested in the topic, some could suspect the presence of ASD, which may have encouraged them to take part in the study. As shown in the study Jurek et al. (48), people with ASD are particularly involved in internet use, which allows them to develop interests related to a specific topic and to make friends with people who share these interests. This may also explain the increased interest in the survey.

As the obtained data shows, there is a positive correlation between age and the level of fear of the COVID-19 pandemic. These results are consistent with other studies (12). Higher levels of fear may be caused by a greater awareness of the possible consequences of the pandemic and a better understanding of the situation. With age, the level of fear about one's own health increases (49). The older the person, the higher the level of fear of death is felt by him (50). COVID-19 is a life-threatening disease in every age group, and more mature people have a more responsible approach to the situation. People in older age groups experience more stressors in everyday life not only in terms of health, but also socioeconomic and educational, which has been highlighted by the pandemic and increased the overall level of fear among them.

This study did not show a statistically significant relationship between the population density in the place of residence, education, SARS-CoV-2 infection and the severity of fear of the COVID-19 pandemic. The limitation of the study was the homogeneity of the group in terms of the above-mentioned features. Another limitation of the study is an overrepresentation of people with AQ ≥32 as it's a disturbance in relation to the general population. We decided to distribute the questionnaire in social media and, as stated before, people who are more interested in the ASD topic, are more eager to fill such a questionnaire, as they might suspect ASD in themselves. Although it's also important to highlight that the survey group does not have a clinical diagnosis of ASD. Next limitation is that the data was collected through an online survey and reached a limited number of respondents. Additionally, the data were collected during the third wave of the pandemic and people knew more about the virus then. They might have felt less fear, as the vaccine had already been distributed.

Overall, the results of the present study showed the impact of the autistic traits on the level of fear of the COVID-19 pandemic. There is a relationship between the symptoms associated with attention switching and the fear felt. It also increases with age. This suggests that people who are more prone to a higher level of fear require more attention during new, stressful situations. These findings are consistent with previous studies that people experiencing higher levels of anxiety and fear are those with special needs during the pandemic and stressful situations (11). Appropriate patterns of attention and interpretation of events may be helpful in dealing with situations that arouse great emotions (50). Establishing a routine for people with ASD may lead to reducing the experienced level of fear (12).

Conclusions

1. The autistic traits affect the level of fear of the COVID-19 pandemic.

2. Of particular importance to the level of fear of the COVID-19 pandemic is the intensity of symptoms in the field of the ability to switch attention.

3. In the study population, there is a positive correlation between age and the level of fear of the COVID-19 pandemic.

4. The population of people with higher autistic traits or ASD requires special attention from health system management bodies in crisis situations.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The research was conducted in accordance with related laws, regulations, and guidelines on research ethics (USTAWA z dnia 5 grudnia 1996 r. o zawodach lekarza i lekarza dentysty). The consent to participate in the survey was obtained.

Author contributions

DB: Investigation, Writing – original draft, Writing – review & editing. AŚ: Investigation, Writing – original draft, Writing – review & editing. AB: Investigation, Writing – original draft, Writing – review & editing. FT: Investigation, Writing – original draft, Writing – review & editing. KW: Conceptualization, Investigation, Methodology, Supervision, Writing – review & editing. MJ-K: Conceptualization, Investigation, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Cecilia Montiel Nava,
The University of Texas Rio Grande Valley,
United States

REVIEWED BY
David Pérez-Jorge,
University of La Laguna, Spain
Francesca Felicia Operto,
University of Salerno, Italy

*CORRESPONDENCE
Mudi H. Alharbi
mhjharbi@taibahu.edu.sa

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Parents' perceptions of the impact of the novel coronavirus (COVID-19) on the eating behaviors and routines of children with autism spectrum disorders (ASD)

Mudi H. Alharbi*

Clinical Nutrition Department, College of Applied Medical Sciences, Taibah University, Madinah, Saudi Arabia

Background: Restricted interests and repetitive behavior are characteristics of autism spectrum disorder (ASD). The likelihood that persons with ASD will respond adversely to unfamiliar situations is great. The novel coronavirus outbreak has resulted in disruptions to all aspects of routine and behavior. Hence, this study proposed to investigate the impact of the outbreak on the eating behavior and routines of children with ASD in Saudi Arabia through the perceptions of their parents.

Method: A cross-sectional study with a quantitative approach was utilized to obtain data from 150 parents of children with ASD aged ≤18 years in Saudi Arabia. The data collected included demographic data of the parents, the ASD status of the family, impact of COVID-19 to the family, eating behavior of the children with ASD, and daily routines of the children with ASD. Moreover, parents were able to provide comments regarding their children's eating behavior or daily routines.

Results: The study found that changes in the eating behavior of children with ASD were found to differ significantly ($p<0.05$) based on the number of children with ASD, the age of the children with ASD, the gender of the children with ASD, and the severity of their ASD symptoms. Moreover, changes to dinner-time routines were found to differ significantly ($p<0.05$) based on the age of the children with ASD. Also, changes to morning routines were found to differ significantly ($p<0.05$) based on the age of the children with ASD, their gender, and the severity of their ASD symptoms. Additionally, impact of COVID-19 to the family had a significant impact to eating behavior and daily routines of the children with ASD.

Conclusion: This study found that the eating behavior and daily routines of children with ASD in Saudi Arabia have been considerably worsened and changed. The study recommends the collaboration of multidisciplinary teams and parents to modify or design interventions that help to change their eating behavior and routine can be implemented in the home. It also recommends the provision of virtual helplines to aid parents of children with ASD in such cases.

KEYWORDS
autism spectrum disorder (ASD), coronavirus, COVID-19, eating behaviors, routines, parents

Introduction

As with other countries across the globe, the Kingdom of Saudi Arabia (KSA) is in the grip of the COVID-19 pandemic. Even before its first case was confirmed on March 2, 2020, the country took several measures to restrict the spread of the disease within the kingdom (1). Eventually, schools and universities were closed on March 8, 2020, together with a ban on gatherings (2). All educational institutions were included in this decision such as, private and public schools, and establishments for vocational and technical training. In their place, online teaching and home-schooling were encouraged (1). Prior research has indicated that reactive closure of schools can dilute the system of societal dealings, diminish and defer the peak of an endemic, and lessen the propagation of influenza, whether regular or epidemic (3, 4).

These measures caused a sudden change of routine for children and their parents as they are required to stay at home in response to the government's directives for social distancing and the closure of schools. In this context, dealing with children with special needs becomes challenging for their families and caregivers. In particular, children with autism spectrum disorder (ASD) experience a considerable change in their routines. For instance, such children typically have several intervention sessions in school, with specialist therapists, or in clinics and institutes dedicated to this purpose. However, due to the measures to contain the contagion, children with ASD have encountered significant disruption to their schedules (5).

Persons with ASD often require long-term support (6) since their symptoms impact day-to-day existence (7). Moreover, their capacity to meet the demands of new situations, learning, and problem-solving are greatly limited (8). Further, there is a greater likelihood that persons with ASD will experience anxiety and depression (9, 10), which may be exacerbated by unfamiliar situations, such as a quarantine (7).

An associated concern for children with ASD is their eating behavior, as many persons with ASD are hypo- or hypersensitive to taste and touch. This indicates that they may be either oversensitive or impervious to the temperature or texture of foods and consequently finicky about food. Consequently, their diet may be restricted to certain foods or specific brands (11). Thus, restricted preferences for food (also termed selective eating, restricted variety, food selectivity, or limited food repertoire) are the problem most frequently associated with feeding in children with ASD (12–14). Prior research in an Omani context has also reported the high occurrence of food selectivity and refusal in children with ASD (15). Moreover, the findings of Vissoker et al. (16) confirmed earlier research on the greater prevalence of eating rigid patterns and eating problems in children with ASD. Further, they highlighted the role of age in this regard. For instance, food selectivity, rituals, and sameness increased with increase in age (16). On the other hand, Patton et al. (17) found that lower consumption of unfamiliar foods, a higher number of instances of behavior that disrupted mealtimes, and a higher number of commands from parents to remind children to take bites during meals were associated with greater severity of ASD (17).

Moreover, in their exploration of the mealtime behavior of children with ASD in the school setting, Padmanabhan and Shroff (18) found that such children struggled at mealtimes if the food was not to their liking, if the food was not what they preferred to eat routinely, and if there had been any change to the schedule of the break times. Further, sensitivity to the smell of food and loudness of others during break times prevented them from consuming their meals. Another facet was related to their tactile sensitivity. That is, they would not eat if the texture of the food was not to their liking (18). Huxham et al. (19) also drew attention to the preference of children with ASD for foods of a certain appearance, for instance according to food color, food presentation and the brand and packaging of food (19). Acceptance of food was also affected by the children's sensory features and food texture. Moreover, Mayes and Zickgraf (20) reported that children with ASD had a greater likelihood of atypical eating behavior than children with ADHD or other disorders, or typically developing children (20). Atypical eating behavior included restricted preferences for food, hypersensitivity to textures of food, other odd patterns such as eating only a certain brand of food, pocketing the food instead of swallowing it, and pica. In the present spread of several epidemics, it is possible that certain foods (or brands of food) that they eat daily may not be easily accessible, which can lead to disturbances in their eating behavior (11).

In addition, Altable (11) emphasized the criticality of routines and control to persons with ASD as they can be disturbed by the minutest and most commonplace alterations (11). Thus, in the context of the COVID-19 pandemic, where routines have been impacted, there is a great likelihood that the daily routines of children with ASD will have been impacted in different ways (11). Eshraghi et al. (21) also highlighted the preoccupation with routine of children with ASD and the high probability of upheaval (emotional and behavioral) due to COVID-19 (21). In an Australian study, Marquenie et al. (22) found that the dinner-time routines of families with young children (2–5 years) with ASD were chaotic and unstructured (22). In contrast, bedtime routines were more structured and, often, non-functional. Moreover, an investigation by Colizzi et al. (23) revealed that various new needs emerged in persons with ASD due to the COVID-19 outbreak (23). For instance, they required greater healthcare support and in-home support, in particular, together with interventions to deal with the disruption caused by the quarantine. Moreover, difficulties in coping with daily activities increased and behavior problems presented more frequently or intensively in one of out of three children with ASD as a minimum. A study conducted in Italy by degli Espinosa et al. (24) highlighted how behavioral support and reinforcement for children with ASD could be provided at home by their parents during the pandemic (24). On the other hand, Stankovic et al. (25) explored the challenges encountered by the parents of children with ASD in Serbia during the COVID-19 situation and found that the absence of support and feelings of helplessness had intensified during this time (25).

Food selection and preferences in ASD

A common related facet of children with ASD, which affects 46% to 89% of such children, is eating challenges (26, 27). Sharp et al. (28, 29) reported that the probability of children with ASD experiencing a feeding problem was five times greater than of children without ASD. Research has indicated that these feeding problems could be a demonstration of the limited interests and activities characteristic of children with ASD (26). A further explanation could be that the behavior of the family could influence the feeding problems of such children either via lowered exposure to a variety of foods (30) or via unintentional support of problem behaviors concerning mealtime (31).

Field et al. (32) highlighted the specific feeding problems encountered in children with ASD. These included refusal of food, selectivity of food by type, selectivity by food by texture, oral motor delays (e.g., chewing, repositioning the tongue, lip closure, etc.), or dysphagia (challenges with swallowing). Children with ASD typically exhibited selectivity by type or texture followed by oral-motor delay leading to mechanical challenges in eating foods; and dysphagia (32). Other studies have reported severe problems with behavior at mealtime (31, 33).

A variety of challenges related to mealtime and eating is experienced by these children and the resulting difficulties can result in insufficient nutrition, disruptive behaviors at mealtime, rigid food-related routines, and intensive effort from members of the family (34–36). The occurrence of disturbances to mealtimes is due to the need of the child with ASD for greater help and supervision, a distinct meal, or since the atmosphere at mealtime is stressful as a result of the extent of attention required by the child with ASD (37).

Ausderau and Juarez (38) noted the commonness of feeding disorders in children with ASD resulting in considerable impacts to their family mealtimes. The study found that while families gave importance to mealtimes, these were often not easy to structure and frequently resulted in the mother's exhaustion. Moreover, the children with ASD exhibited unusual preferences for food, food selectivity, and disruptive behaviors at mealtime (38). In another study, Aponte and Romanczyk (39) examined the association between feeding problems and autism severity. They found that various feeding problems and the duration of negative vocalizations during observations of meals were predicted by autism severity.

BalikçCheck that all equations and special characters are displayed correctly.i and Çiyiltepe (40) used the BAMBI (Brief Autism Mealtime Behavior Inventory) (41, 42) to study the feeding problems of children with ASD. Their study found that the feeding problems exhibited by children with ASD included behavioral problems at mealtime, such as sobbing and screaming throughout meals followed by avoidance of certain food types and textures, selectivity of type and texture, and dislike of some food types and textures (40). In another study, Bandini et al. (43) found that in contrast to children without ASD, children with ASDs displayed more food refusal and more limited repertoire of food. A later study by Bandini et al. (14) evaluated food selectivity of children with ASD in a longitudinal study. Overall, an improvement in food refusal could be seen between baseline and follow-up. However, the food repertoire namely, number of distinctive foods partaken, did not seem to increase.

In a Turkish study, Bicer and Alsaffar (12) studied the dietary intake and feeding problems of 164 children (aged 4–18 years) and reported that the most typical feeding problems of these children were consuming a restricted range of foods (food selectivity), rapid eating, and overeating. Correspondingly, common strategies adopted by parents/caregivers to address these feeding problems included distraction, permitting more drinking of fluids, and offering preferred foods. Other approaches utilized included compelling, offering rewards, wheedling, child-led feeding, giving meals a miss, chastisement, and utilizing high-calorie supplements/formula.

Mahmoud et al. (44) contrasted the feeding behavior of 35 children aged 2 - 4 years recently diagnosed with ASD with 70 children who were typically developing (TD). This study reported that children with ASD demonstrated a greater extent of challenging feeding behaviors, such as feed neophobia, consuming non-food items, needing help when eating, and avoidance of food of certain taste or texture (44). Furthermore, Gray and Chiang (45) reported that the problematic mealtime behaviors exhibited by Chinese-American children with ASD included preference for certain food textures (e.g., crunchy), unwillingness to try new foods, and inability to stay seated at the table till the end of the meal.

Determinants of feeding difficulties

Various facets have been recognized to influence feeding difficulties of children with ASD. These include age, ASD severity, and ASD symptoms, (46) among others. The relationship between age of a child with ASD and difficulties in feeding has been studied by various researchers with two reporting that these were negatively related (14, 47), that is, eating difficulties may diminish as the child grows older; one reporting a favorable relationship (16); and three reporting no relationship (48–50). On the other hand, concerning the relationship between ASD symptoms and their severity, with difficulties in feeding, researchers have reported favorable or no relationship. For example, Pham et al. (51) reported a positive association whereas Prosperi et al. (52); Sharp et al. (28, 29); and Smith et al. (50) reported that there was no relationship between feeding difficulties and ASD symptoms and their severity. Moreover, while Pham et al. (51) noted that the incidence of food selectivity corresponded to increased ASD severity, that is, to severe from moderate and to moderate from mild. In contrast, some other studies (13, 53) reported that the method of assessment, such as the usage of Autism Diagnostic Interview-Revised (ADI-R) (54), Autism Diagnostic Observation Scale-Calibrated Severity Scale (ADOS-CSS) (55), Social Responsiveness Scale (SRS) (56), BAMBI, among others, influenced the relationship between feeding difficulties and severity of ASD symptoms.

The role of gender has also been studied, though not specifically. For instance, Seiverling et al. (57) reported that boys with ASD were more likely to have feeding challenges than girl children with ASD. Leader et al. (58) also reported that gender was significantly associated with food selectivity. On the other hand, Worley and Matson (59) found that there the differences among the genders was not significant for eating problems, such as over/under eating. Also, Babinska et al. (60) found that food selectivity, problems at mealtime, diet, and usage of food supplements had no interactions with gender. That is, high incidences of challenging behavior associated with food intake were seen in both genders regardless of age. However, severity of symptoms was found to be correlated to challenging eating behavior.

Routines and ASD

Routines are defined as “observable, repetitive behaviors which directly involve the child and at least one adult acting in an interactive or supervisory role, and which occur with predictable regularity in the daily or weekly life of the child” and “may occur at a regular time, in the presence of a regular adult, in a regular place, in a regular sequence, or a combination of these” (61, p. 243). Routines are considered to be essential in establishing the basis for development of ritual. Rituals, in their turn, are regarded as significant in developing a family unit that is robust and healthy (22). In families of children with ASD, the daily routines are often centered around the characteristic demands of the child rather than those of the family in its entirety (62). Moreover, children with ASD can frequently find it difficult to participate in daily routines in their home, such as bath or bed time (63). Boyd et al. (64) reported that there were some common facets of research related to family routines and families of children with ASD. The facets were stress related to the necessity for and challenges with routines, the connection between family routines and the family’s health, participation of the family as planned around the child with ASD, adherence to routines while encountering challenges, cumbersome routines, significant routines for bonding of the family, and adaptations made by families to routines. Henderson et al. (65) found that quality and hygiene of sleep were associated with not only routines but also externalizing behaviors in a group of 58 children with ASD.

Marquenie et al. (22) found that families of children aged 2-5 years with ASD experienced dinnertime routines that were unruly and unstructured. In contrast, bedtime routines involved routines that were more structured and often non-functional. Thus, in contrast to dinnertime routines, bedtime routines were involved significant rituals and interactions. In another study, Ibañez et al. (63) used a randomized controlled trial to scrutinize the effectiveness of an interactive, web-based tutorial for parents in enhancing the engagement of children with ASD (aged 18-60 months) in everyday routines. This study found that the use of such a tutorial enhanced child participation in routines.

Stoppelbein et al. (66) used the Child Routines Questionnaire (CRQ) (61) to compare details of the routines of 45 children with ASD and 45 typically developing children of matching ages/genders. The parents of the children in the ASD group were found to report fewer routines. Moreover, children with ASD were found to have greater internalizing and externalizing symptoms than the children without ASD. In addition, the routine levels of younger children with ASD were found to be lower than those of older children (66). Mirzaie et al. (67) reported that it was difficult for families of children with ASD to follow routines due to different reasons, such as the children’s lack of flexibility, challenging behaviors, problems with sensory-processing, anxiety or marital issues of parents, and environmental aspects including poor access to ASD-related healthcare services in areas that were remote and less populated. McAuliffe et al. (68) highlighted that the efforts needed to develop family routines were substantial and that these could be at the detriment of the health and wellbeing of mothers of children with ASD.

Impacts of COVID-19

COVID-19 disrupted routines, school activities and special programs, day programs, and also support at work (11). Baweja et al. (69) reported that the different challenges encountered by persons with ASD during the COVID-19 pandemic included disruptions owing to changes in education and vocation, challenges to routines associated with home and leisure, restricted obtainability of behavioral health services, and modifications in delivery of health services. Individuals with ASD were more vulnerable due to their characteristics and typically accompanying conditions (69).

Narzisi (5) highlighted that children with autism spectrum conditions (ASC) typically have interventions for many hours a week, either at their homes with trained therapists or in assigned institutions or hospitals. Nevertheless, due to the COVID-19 pandemic, the physical support provided by therapists to these children and their families could not be continued. Moreover, they could not go to external interventions (5). Persons with ASD typically receive therapy in different ways (e.g., speech, physical, behavioral, social, occupational, and psychological). However, with COVID-19, persisting with these therapies was largely impossible (11). Manning et al. (70) found that the predominant facets of stress in families of persons with ASD were related to disruption of therapeutic service, finances, and illness. Moreover, higher stress was reported for caregivers of persons who had received a high intensity of services prior to COVID-19. The main concerns voiced by the respondents were related to obtaining respite care during the pandemic (70).

The present study

The aim of this study was to investigate the eating behavior and routines of children with ASD in Saudi Arabia during the COVID-19 outbreak. Two research questions informed the study: (1) What is the impact of COVID-19 on the eating behavior of children with ASD in the KSA? and (2) What is the impact of COVID-19 on their daily routines? Based on these research questions, the study hypothesized that the eating behavior of children with ASD and their daily routines could have significantly worsened in comparison to their typical state prior to the closure of schools. This study is significant because it endeavors to draw attention to the current status of children with ASD in the KSA in this regard and to provide insights for appropriate supportive action.

The scrutiny of prior research suggested that the pandemic would impact eating behavior and routines of children with ASD. The impact of different determinants (e.g., Age, Gender, and

Severity of ASD symptoms) on children's difficulties with feeding was another facet that has been explored in prior literature (46) and was thus included in the study for scrutiny extending the consideration to routines as well. Figure 1 depicts the proposed conceptual model for the study.

Method

Measures

A total of 150 Saudi parents of children with ASD were invited to participate in this survey as part of a cross-sectional study. The children described in the study were aged ≤18 years. The survey or questionnaire was distributed using email by contacting different Autism institutions. A questionnaire was designed in English and subsequently translated into Arabic. The following data were collected in the period April, 2020 to May, 2021:

(1) demographic data of the parents such as gender, age, marital status, educational qualifications, family income, current working situation (6 items);
(2) family ASD status such as number of children with/without ASD, age of children with ASD, gender of children with ASD, severity of ASD symptoms (5 items);
(3) impact of COVID-19 restrictions on family (10 items) adapted from COVID-related studies (23, 70). This scale used a five-item Likert scale: 1-No impact; 2-Little impact; 3-Impacted to some extent; 4-High impact; 5-Very high impact;
(4) eating behavior of children with ASD (12 items) adapted from the findings of various studies e.g., (20). This scale used a five-item Likert scale: 1–Considerably improved, 2–Slightly improved, 3–No different, 4–A little worse, and 5–Very much worse; and
(5) daily routines of children with ASD (16 items) modified from the Daily Routine and Autonomy (DRA) questionnaire and the findings of other studies e.g., (22, 71). The DRA questionnaire was developed by Lamash and Josman (71) in acknowledgement of the limited independence displayed by persons with ASD in daily activities. This study utilized sections of the questionnaire that were deemed suitable for a wider sample of children with ASD. Again, this scale used a five-item Likert scale: 1–Considerably improved, 2–Slightly improved, 3–No different, 4–A little worse, and 5–Very much worse.

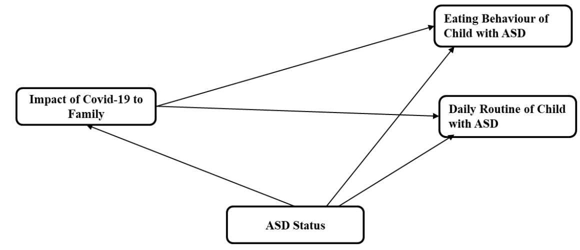

FIGURE 1
Conceptual model.

At the end of the questionnaire, space was provided for the parents to add further comments or notes related to their children's eating behavior or daily routines. This study was carried out in accordance with the Declaration of Helsinki and with the approval of ethics committee of applied medical sciences at Taibah university no, 2020/52/201/CLN.

Statistical analyses

Children's ASD behaviors during the COVID-19 outbreak were rated by their parents using the Arabic or English version of the questionnaire. The validation was assessed. The study utilized different statistical analyses such as frequencies and percentages, descriptive statistics (mean (M) and standard deviation (SD)), and inferential statistics (one-sample t-test, one-way ANOVA, and regression). These analyses served to assess the changes to eating behavior and daily routines of the children with ASD. Moreover, the impact of the family ASD status on eating behavior and daily routines was also analyzed. All tests were performed using SPSS software version 26.0. The questionnaire was presented to a group of specialists in the field of nutrition and special education in ASD. Hence, the internal consistency coefficients were extracted for the overall instrument and for each individual domain using Cronbach's alpha formula. The value of the alpha coefficient for the instrument as a whole unit was 0.85. The value of the alpha coefficient was 0.84 for the first domain (eating behavior), and 0.86 for the second domain (eating routines).

Results

Demographic information

The majority of the participating parents were female (66.0%) and aged between 21 and 30 years (50.0%). Moreover, the majority of the parents were still married (81.3%), were graduates (69.3%), and had a family income between 10,000 and 15,000 SAR (46.7%). Further, 8% were not working due to COVID-19, having lost their jobs during the pandemic, indicating that the pandemic had impacted the livelihood of these parents. A large proportion of the participating parents (70.7%) were able to work from home. The demographic details of the parents are summarized in Table 1.

Family ASD status

The majority of the participating families had one child with ASD (96.0%) and one or two children without ASD (70.0%). The ages of the children with ASD were mostly 3–5 years (52.7%) followed by ages of 6–10 years (25.3%). The majority of the children with ASD were male (62.7%). The severity of their symptoms was mostly moderate (64.0%), followed by mild symptoms (28.0%). There were also a few (8.0%) children with ASD who had severe symptoms. Also (Table 2).

Children's eating behavior in the pandemic

A one-sample t-test, utilized to assess the parents' perceptions of the changes to their children's eating behavior and daily routines in the pandemic, revealed that the children's eating behavior (M=3.805, SD=0.444) had significantly worsened in comparison to their normal state (95% CI=3.73–3.88), which was significantly higher than the rating of "3" – (Not different) with median 4 (A little worse), p<.001 (Table 3).

Further, from Table 4 it could be seen that the three facets of eating behavior that had changed the most were "*Rejection of food based on color or shape*" (M=4.693, SD=0.655); "*Rejection of food based on texture*" (M=4.500, SD=0.833); and "*Eating only certain kinds of food (e.g., grain products, chicken, fruit, French fries, etc.)*" (M=4.313, SD=0.604). The three facets of eating behavior that had changed the least were "*Exhibiting pica (that is, eating non-food substances such as crayons, dirt, soap, etc.)*" (M=2.727, SD=1.088); "*Smelling foods before eating*" (M=2.933, SD=1.168); and "*Not mixing foods before eating*" (M=3.187, SD=0.878).

TABLE 1 Parents' Demographic information.

Demographics	Categories	Frequency	Percent
Gender of parent	Male	51	34.0
	Female	99	66.0
Age (Years)	21-30	75	50.0
	31-40	61	40.7
	41-50	14	9.3
Marital Status	Married	122	81.3
	Divorced	28	18.7
Educational Qualification	High School or diploma	41	27.3
	Graduate	104	69.3
	Post-graduate	5	3.3
Family income	<5000 SAR	2	1.3
	5000 – <10000 SAR	65	43.3
	10000 – 15000 SAR	70	46.7
	>15000 SAR	13	8.7
Current working situation for the parents	Not working before Covid-19	2	1.3
	Not working due to Covid-19	12	8.0
	Working from home	106	70.7
	Commuting to work	30	20.0
Total		**150**	**100.0**

Children's daily routines in the pandemic

Similarly, it could be seen that the daily dinner-time routines of the children (M=3.593, SD=0.483) had significantly worsened in comparison to their state prior to the pandemic (95% CI=3.8746–4.0304, P<0.001). Likewise, the morning (M=4.265, SD=0.513, 95% CI=4.1822–4.3478, P<0.001) and bedtime (M=3.555, SD=0.483, 95% CI=3.4771–3.6329, P<0.001) routines had also significantly worsened in comparison with their state prior to the pandemic (Table 5).

From Table 6, it could be seen that the dinner-time routine that had deteriorated the most was "*Range of foods to eat*" (M=4.313, SD=0.787), whereas the morning routine that had deteriorated the most was "*Willingness to dress*" (M=4.487, SD=0.833). The bedtime routine that had deteriorated the most was "*Willingness to keep clothes ready for the next day*" (M=4.020, SD=0.893). Overall, all the facets of the morning routine appeared to have deteriorated the most. Some facets of the dinner-time routines and bedtime routines had deteriorated slightly in comparison, such as "*Usage of preferred plates, spoons, glasses, etc.*" (M=3.547, SD=0.931) and "*Need for certain pillow/blanket*" (M=3.680, SD=0.805). Also, although the mean of the parents' perceptions regarding the children's "*Willingness for the light to be switched off*" indicated slight improvement to no change (M=2.593, SD=0.991).

Influence of family status on eating behavior and daily routines

As can be seen in Table 7, the change in the eating behavior of a child with ASD was found to differ significantly (p<0.05) based on the number of children with ASD, age of children with ASD, gender of children with ASD, and severity of their ASD symptoms. However, *change in eating behavior* did not differ significantly based on number of children without ASD. *Changes to dinner-time routines* were found to differ significantly (p<0.05) based on the age of children with ASD, but not on the number of children with or without ASD, gender of children with ASD, and severity of their ASD symptoms. *Changes to morning routines* were found to differ significantly (p<0.05) based on age of children with ASD, their gender, and the severity of their ASD symptoms, but not number of children with or without ASD. *Changes to bedtime routines* were found to differ significantly (p<0.05) based on the age of children with ASD but not with the number of children with or without ASD, gender of children with ASD, or severity of their ASD symptoms.

TABLE 2 Family ASD status.

Variable	Category	Median*	Frequency	Percentage
Number of children with ASD	1	1	144	96.0
	2		6	4.0
Number of children without ASD	1	2	69	46.0
	2		70	46.7
	3		11	7.3
Age of children with ASD (Years)	≤ 2	2	18	12.0
	3 – 5		79	52.7
	6 – 10		38	25.3
	11 – 18		15	10.0
Gender of children with ASD	Male	1	94	62.7
	Female		56	37.3
Severity of ASD symptoms	Mild		42	28.0
	Moderate	2	96	64.0
	Severe		12	8.0
Total			**150**	**100.0**

*Age of children with ASD;2 = 3-5 years old. Gender of children with ASD: 1= male. Severity of ASD symptoms; 2= Moderate.

Influence of impact of COVID-19 on family eating behavior

A multiple linear regression was used to test the impact of COVID-19 on the family's eating behavior (Tables 8, 9). This resulted in a significant model, F(1,148) = 10.670, p <.01, R2 = 0.067. The individual predictors were then scrutinized further and the outcomes indicated that while Impact of COVID-19 to family was a significant predictor (t=3.267, p<0.001), the overall facets of family ASD status were not significant predictors. The number of children with ASD was found to be a significant predictor in the early stages of the regression (t=2.048, p<0.05), but its impact was reduced when the other variables were added to the regression analysis.

Influence of impact of COVID-9 on family daily routines

Influence of impact of COVID-19 on family dinner time routines

A multiple linear regression was used to test the impact of COVID-19 on the family's dinner time routines (Tables 10, 11). This again resulted in a significant model, F(1, 148) = 4.460, p < 0.05, R2 = 0.036. The individual predictors were then scrutinized further and the outcomes indicated that while Impact of COVID-19 to family was a significant predictor (t=2.337, p<0.05), the facets of family ASD status were not significant predictors.

Influence of impact of COVID-19 on family morning routines

A multiple linear regression was used to test the impact of COVID-19 on the family's morning time routines (Tables 12, 13). This again resulted in a significant model, F(1, 148) = 5.769, p < 0.05, R2 = 0.038. The individual predictors were then scrutinized further and the outcomes indicated that while Impact of COVID-19 to family was a significant predictor (t=2.402, p<0.05), the facets of family ASD status were not significant predictors.

Influence of impact of COVID-19 on family bedtime routines

A multiple linear regression was used to test the impact of COVID-19 on the family's bed time routines (Tables 14, 15). This again resulted in a significant model, F(1, 148) = 31.986, p < 0.01,

TABLE 3 Parents' perceptions regarding changes in eating behavior of children with ASD.

	Median	Mean	SD	Sig.	95% Confidence Interval (CI) of the Difference
Eating Behavior of Child with ASD	4*	3.805	0.444	<0.001	3.7334 – 3.8766

*4=A little worse.

TABLE 4 Changes to eating behavior.

Statements	Median*	M	SD
Acceptance or preference of different foods	4	4.207	0.862
Rejection of food based on texture	5	4.500	0.833
Rejection of food based on temperature	4	3.733	0.711
Rejection of food based on color or shape	5	4.693	0.655
Pocketing of food without swallowing it	4	3.980	0.573
Eating only certain kinds of food (e.g., grain products, chicken, fruit, French fries, etc.)	4	4.313	0.604
Eating only certain brands of a food	4	4.047	0.698
Not mixing foods before eating	3	3.187	0.878
Smelling foods before eating	3	2.933	1.168
Using only a certain plate or cup	3	3.420	0.853
Preferring food to be presented in a specific manner	4	3.927	0.419
Exhibiting Pica (that is, eating non-food substances such as, crayons, dirt, soap, etc.)	2	2.727	1.088

*1=Considerably improved, 2=Slightly Improved, 3=Not different, 4=A little worse, 5=Very much worse.

R2 = 0.178. The individual predictors were then scrutinized further and the outcomes indicated that while Impact of COVID-19 to family was a significant predictor (t=5.656, p<0.001), the facets of family ASD status were not significant predictors apart from Number of children without ASD (t=2.819, p<0.05).

Parents' comments

About (35%) of parents' comments at the end of the questionnaire indicated that their children lost weight compared to the period before the pandemic and they had encountered different challenges due to the COVID-19 situation, specifically with regard to procurement of the specific brands of food preferred by their children with ASD. Moreover, 40% indicated that dealing with multiple children with ASD requires planning and advice should be less cumbersome.

Discussion

To the best of the researcher's knowledge, this is one of the first studies placing emphasis on the eating behavior and daily routines of children with ASD in Saudi Arabia during the coronavirus outbreak. Overall, the study found that parents perceived that the behaviors of their children with ASD concerning these had deteriorated due to the pandemic-related change in their situations.

Current status of eating behavior and daily routines

The study found that the children's eating behavior had significantly worsened in comparison to their normal state in the pre-pandemic context. Eating challenges are a characteristic of most children with ASD (26, 27). The aspects of eating behavior that had changed the most were rejection of food based on color or shape, and texture and increased consumption of only certain kinds of food. This was in line with prior studies which have highlighted that selectivity of food by type and texture are common in children with ASD (32, 40). Moreover, the findings confirm that the food repertoire of a child with ASD does not typically change with time (14). This is further confirmed by the finding that the facets of eating behavior that had changed the least were related to pica; smelling foods prior to eating; and not mixing foods prior to eating.

Further, the study found that the daily routines of the children with ASD had also worsened. These findings were in line with Altable (11) and Eshraghi et al. (21), who highlighted that the daily routines of children with ASD have been impacted due to the pandemic in different ways. In particular, the parents perceived that the children's morning routines were the most impacted, followed by the dinner-time routines and bedtime routines. It is possible that the dinner-time and bedtime routines were not impacted as much as the morning routines because the morning routines would usually have involved the child getting ready (or being readied) to leave the house to attend school or an intervention session. Prior research (22, 62, 63) has highlighted that bedtime routines were typically the most structured whereas dinnertime routines were more disordered, though children with ASD can find it difficult to participate in such routines. Nevertheless, it could be inferred that the disruption of the routines of the child with ASD had consequences for the families of the participants of the study.

Relationships between impact of COVID-19 to family, eating behavior, daily routines, and family ASD status

The study found that the change in the eating behavior of a child with ASD was found to differ significantly based on the

TABLE 5 Parents' perceptions regarding changes in daily routines of children with ASD.

	Median*	M	SD	Sig.	95% Confidence Interval (CI) of the Difference
Dinner time routines	4	3.953	0.483	<0.001	3.8746 – 4.0304
Morning routines	4	4.265	0.513	<0.001	4.1822 – 4.3478
Bedtime routines	4	3.555	0.483	<0.001	3.4771 – 3.6329

*4=A little worse.

TABLE 6 Changes to daily routine.

Statements	Median	Mean	Std. Deviation
Dinner time routines			
Range of foods to eat	4	4.313	0.787
Usage of preferred plates, spoons, glasses, etc.	3	3.547	0.931
Usage of same chair at dinner table	4	3.680	0.805
Need for same position at dinner table	4	4.160	0.696
Refusal to feed himself/herself	4	4.087	0.919
Retching when certain foods are seen/presented	4	3.807	0.808
Throwing tantrums at the dinner table	4	4.067	0.960
Eating with the family	4	3.967	0.915
Morning routines			
Willingness to brush teeth	4	4.207	0.688
Willingness to bathe	4	4.120	0.723
Willingness to go to the toilet	4	4.227	0.820
Willingness to dress	5	4.487	0.833
Bedtime routines			
Willingness to change into night clothes	4	3.927	0.419
Willingness for the light to be switched off	2	2.593	0.991
Need for certain pillow/blanket	4	3.680	0.805
Willingness to keep clothes ready for the next day	4	4.020	0.893

*1=Considerably improved, 2=Slightly Improved, 3=Not different, 4=A little worse, 5=Very much worse.

number of children with ASD, age of children with ASD, gender of children with ASD, and severity of their ASD symptoms. Consistent with prior studies, the changes to the eating behavior of the children with ASD was related to the severity of their ASD symptoms (17) and also their age (14, 16, 47). Eating behavior was also related to the gender of the children (57, 58). Changes to the eating behavior of the children with ASD was also related to the number of children with ASD in the family. To the researcher's best knowledge, this aspect has not been previously explored in research.

Moreover, on the lines of the findings of Huxham et al. (19) and Padmanabhan and Shroff (18), this study found that the facets of eating behavior that the children appeared to struggle with included their preference for foods of certain colors, shapes, textures, kinds, or brands, and for food to be presented in a particular manner. Other eating behavior had also deteriorated, such as pocketing of food in contrast to swallowing it (20).

The study found that the worsening of dinner-time routines was related to the age of the child with ASD but not to their gender or the severity of their symptoms. Also, it was not related to the number of children with and without ASD in the family. The worsening of morning routines was found to be related to the age of the child with ASD, their gender, and the severity of symptoms, but not to number of children with and without ASD in the family. Finally, the parents' perceptions of the bedtime routines were found to be related to the age of the child with ASD. The study's findings on the relationship between the age of the children with ASD and their routines were on the lines of Marquenie et al. (22) and Stoppelbein et al. (66). Moreover, the scrutiny on the associations between gender, ASD severity, and routines does not seem to have received much consideration although Stoppelbein et al. (66) did not find a significant relationship between gender and child routines and severity and child routines.

Furthermore, from the parents' notes, this study found that the COVID situation had made it difficult for parents to obtain the brands of food their children preferred. This could have contributed to the worsening of the children's eating behavior and consequently some of the activities involved in their mealtime routines.

Conclusion

This study found that the eating behavior and daily routines of children with ASD in Saudi Arabia considerably worsened during the coronavirus pandemic. Given that the ongoing and the attempts of governments in Saudi Arabia and across the world to contain the situation have met with mixed success, it is possible that this situation may be returned. In such case, the closing of educational institutions for children with ASD. In this context, this study highlights the impacts on the behavior of children with ASD due to changes in their regular routines, which might include regular attendance at mainstream or special schools and a variety of interventions.

Moreover, by obtaining the perceptions of the parents of children with ASD across different age groups (≤18 years) and of mixed gender and varying levels of severity of ASD symptoms, this study highlights the fact that changes in schedule or context do impact children with ASD regardless of their age, gender, or ASD severity. A downstream impact of the effects on children with ASD is the impact on their parents' wellbeing (25). Consequently, it is imperative that measures be taken to help children with ASD deal with such epidemic-related situations and to prepare them for the changes that may lie ahead.

Limitations of the study

This study is not without limitations. Firstly, the study was undertaken after pandemic-related precautions were implemented in Saudi Arabia. Consequently, it is possible that some measures may already have been undertaken to mitigate the impact on children with ASD. Future researchers could seek to overcome these limitations by undertaking a study with a broader sample and by performing a longitudinal study where the impacts on children with ASD are scrutinized at different points in the pandemic

TABLE 7 Influence of family status on eating behavior and daily routines.

Family Status	Categories	n (%)	Eating Behavior of Child with ASD		Dinner time routines		Morning routines		Bedtime routines	
			Mean ± SD	p-value	Mean ± SD	p-value	Mean ± SD	p-value	Mean ± SD	p-value
Number of children with ASD	1	144 (96.0)	3.787 ± 0.438	(0.015)	3.950 ± 0.491	(0.725)	4.257 ± 0.514	(0.348)	3.545 ± 0.483	(0.222)
	2	6 (4.0)	4.236 ± 0.406		4.021 ± 0.243		4.458 ± 0.510		3.792 ± 0.459	
Number of children without ASD	1	69 (46.0)	3.809 ± 0.348	(0.520)	3.957 ± 0.367	(0.528)	4.236 ± 0.460	(0.144)	3.467 ± 0.351	(0.119)
	2	70 (46.7)	3.824 ± 0.532		3.925 ± 0.582		4.332 ± 0.561		3.625 ± 0.595	
	3	11 (7.3)	3.659 ± 0.362		4.102 ± 0.443		4.023 ± 0.467		3.659 ± 0.302	
Age of children with ASD (Years)	≤ 2	18 (12.0)	3.787 ± 0.441	(0.001)	4.097 ± 0.547	(0.033)	4.403 ± 0.447	(0.005)	3.639 ± 0.260	(0.002)
	3 – 5	79 (52.7)	3.921 ± 0.338		4.000 ± 0.288		4.351 ± 0.432		3.563 ± 0.383	
	6 – 10	38 (25.3)	3.735 ± 0.231		3.905 ± 0.323		4.164 ± 0.436		3.664 ± 0.488	
	11 – 18	15 (10.0)	3.389 ± 0.780		3.650 ± 1.113		3.900 ± 0.855		3.133 ± 0.906	
Gender of children with ASD	Male	94 (62.7)	3.887 ± 0.363	(0.003)	3.957 ± 0.464	(0.872)	4.330 ± 0.418	(0.045)	3.350 ± 0.416	(0.246)
	Female	56 (37.3)	3.668 ± 0.530		3.944 ± 0.518		4.156 ± 0.418		3.496 ± 0.557	
Severity of ASD symptoms	Mild	42 (28.0)	3.808 ± 0.402	(0.006)	3.988 ± 0.372	(0.789)	4.179 ± 0.446	(0.001)	3.482 ± 0.328	(0.511)
	Moderate	96 (64.0)	3.852 ± 0.428		3.945 ± 0.510		4.357 ± 0.522		3.586 ± 0.533	
	Severe	12 (8.0)	3.424 ± 0.557		3.885 ± 0.623		3.833 ± 0.417		3.563 ± 0.285	

timeline. Additionally, it appeared that the parents were experiencing some form of fatigue in responding to the questionnaire, perhaps due to the surfeit of similar studies being undertaken across the globe.

Moreover, no data were explicitly collected related to the pre-pandemic status of the children of the participating families. A future researcher could rectify this situation. An additional facet could be the involvement of external stakeholders, such as

TABLE 8 Model summary for influence of impact of COVID-19 on family eating behavior.

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	Change Statistics			
						F Change	df1	df2	Sig. F Change
1	0.259	0.067	0.061	0.969	0.067	10.670	1	148	0.001
2	0.305	0.093	0.081	0.959	0.026	4.195	1	147	0.042
3	0.306	0.093	0.075	0.962	0.000	0.052	1	146	0.821
4	0.307	0.094	0.069	0.965	0.001	0.127	1	145	0.723
5	0.327	0.107	0.076	0.961	0.013	2.093	1	144	0.150
6	0.328	0.108	0.070	0.964	0.000	0.057	1	143	0.811

TABLE 9 Path Coefficient for influence of impact of COVID-19 on family eating behavior.

Model	Independent variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	0.000	0.079		0.000	1.000
	Impact of COVID-19 to family	0.259	0.079	0.259	3.267	0.001
2	(Constant)	0.000	0.078		0.000	1.000
	Impact of COVID-19 to family	0.241	0.079	0.241	3.046	0.003
	Number of children with ASD	0.162	0.079	0.162	2.048	0.042
3	(Constant)	0.000	0.079		0.000	1.000
	Impact of COVID-19 to family	0.242	0.080	0.242	3.045	0.003
	Number of children with ASD	0.161	0.079	0.161	2.028	0.044
	Number of children without ASD	-0.018	0.079	-0.018	-0.227	0.821
4	(Constant)	0.000	0.079		0.000	1.000
	Impact of COVID-19 to family	0.238	0.081	0.238	2.940	0.004
	Number of children with ASD	0.162	0.080	0.162	2.031	0.044
	Number of children without ASD	-0.011	0.082	-0.011	-0.138	0.890
	Age of children with ASD	-0.029	0.082	-0.029	-0.356	0.723
5	(Constant)	0.000	0.078		0.000	1.000
	Impact of COVID-19 to family	0.231	0.081	0.231	2.854	0.005
	Number of children with ASD	0.153	0.080	0.153	1.925	0.056
	Number of children without ASD	0.006	0.082	0.006	0.076	0.940
	Age of children with ASD	-0.029	0.082	-0.029	-0.359	0.720
	Gender of children with ASD	-0.116	0.080	-0.116	-1.447	0.150
6	(Constant)	0.000	0.079		0.000	1.000
	Impact of COVID-19 to family	0.230	0.081	0.230	2.833	0.005
	Number of children with ASD	0.153	0.080	0.153	1.914	0.058
	Number of children without ASD	0.002	0.084	0.002	0.024	0.981
	Age of children with ASD	-0.029	0.082	-0.029	-0.351	0.726
	Gender of children with ASD	-0.116	0.080	-0.116	-1.448	0.150
	Severity of ASD symptoms	0.019	0.081	0.019	0.239	0.811

TABLE 10 Model summary for influence of impact of COVID-19 on family dinner time routines.

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	0.189	0.036	0.029	0.9854	0.036	5.460	1	148	0.021
2	0.189	0.036	0.023	0.9886	0.000	0.020	1	147	0.888
3	0.195	0.038	0.018	0.9909	0.002	0.339	1	146	0.561
4	0.197	0.039	0.012	0.9939	0.001	0.114	1	145	0.736
5	0.197	0.039	0.005	0.9973	0.000	0.004	1	144	0.948
6	0.244	0.059	0.020	0.9899	0.021	3.154	1	143	0.078

TABLE 11 Path Coefficient for influence of impact of COVID-19 on family dinner time routines.

Model	Independent variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	0.000	0.080		0.000	1.000
	Impact of COVID-19 to family	0.189	0.081	0.189	2.337	0.021
2	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.187	0.082	0.187	2.298	0.023
	Number of children with ASD	0.012	0.082	0.012	0.141	0.888
3	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.183	0.082	0.183	2.230	0.027
	Number of children with ASD	0.014	0.082	0.014	0.168	0.866
	Number of children without ASD	0.048	0.082	0.048	0.583	0.561
4	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.187	0.083	0.187	2.249	0.026
	Number of children with ASD	0.013	0.082	0.013	0.159	0.874
	Number of children without ASD	0.041	0.084	0.041	0.487	0.627
	Age of children with ASD	0.029	0.084	0.029	0.338	0.736
5	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.188	0.084	0.188	2.241	0.027
	Number of children with ASD	0.013	0.083	0.013	0.163	0.871
	Number of children without ASD	0.040	0.085	0.040	0.470	0.639
	Age of children with ASD	0.029	0.085	0.029	0.337	0.736
	Gender of children with ASD	0.005	0.083	0.005	0.066	0.948
6	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.194	0.083	0.194	2.330	0.021
	Number of children with ASD	0.016	0.082	0.016	0.196	0.845
	Number of children without ASD	0.072	0.087	0.072	0.832	0.407
	Age of children with ASD	0.025	0.084	0.025	0.291	0.771
	Gender of children with ASD	0.009	0.082	0.009	0.114	0.909
	Severity of ASD symptoms	-0.148	0.083	-0.148	-1.776	0.078

TABLE 12 Model summary for the impact of COVID-19 on family morning routines.

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	Change Statistics			
						F Change	df1	df2	Sig. F Change
1	0.194	0.038	0.031	0.984	0.038	5.769	1	148	0.018
2	0.208	0.043	0.030	0.985	0.006	0.885	1	147	0.348
3	0.210	0.044	0.024	0.988	0.001	0.120	1	146	0.729
4	0.222	0.049	0.023	0.988	0.005	0.810	1	145	0.370
5	0.222	0.049	0.016	0.992	0.000	0.005	1	144	0.946
6	0.226	0.051	0.011	0.994	0.002	0.260	1	143	0.611

TABLE 13 Path Coefficient for the impact of COVID-19 on family morning routines.

Model	Independent variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	0.000	0.080		0.000	1.000
	Impact of COVID-19 to family	0.194	0.081	0.194	2.402	0.018
2	(Constant)	0.000	0.080		0.000	1.000
	Impact of COVID-19 to family	0.185	0.081	0.185	2.278	0.024
	Number of children with ASD	0.076	0.081	0.076	0.941	0.348
3	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.182	0.082	0.182	2.230	0.027
	Number of children with ASD	0.078	0.082	0.078	0.953	0.342
	Number of children without ASD	0.028	0.081	0.028	0.347	0.729
4	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.170	0.083	0.170	2.056	0.042
	Number of children with ASD	0.080	0.082	0.080	0.977	0.330
	Number of children without ASD	0.046	0.084	0.046	0.546	0.586
	Age of children with ASD	-0.076	0.084	-0.076	-0.900	0.370
5	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.170	0.083	0.170	2.041	0.043
	Number of children with ASD	0.079	0.082	0.079	0.966	0.336
	Number of children without ASD	0.046	0.085	0.046	0.548	0.585
	Age of children with ASD	-0.076	0.084	-0.076	-0.897	0.371
	Gender of children with ASD	-0.006	0.083	-0.006	-0.068	0.946
6	(Constant)	0.000	0.081		0.000	1.000
	Impact of COVID-19 to family	0.172	0.084	0.172	2.055	0.042
	Number of children with ASD	0.080	0.082	0.080	0.972	0.332
	Number of children without ASD	0.056	0.087	0.056	0.641	0.523
	Age of children with ASD	-0.077	0.085	-0.077	-0.908	0.365
	Gender of children with ASD	-0.004	0.083	-0.004	-0.054	0.957
	Severity of ASD symptoms	-0.043	0.084	-0.043	-0.510	0.611

TABLE 14 Model summary for the impact of COVID-19 on family bedtime routines.

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	0.422	0.178	0.172	0.910	0.178	31.986	1	148	0.000
2	0.426	0.182	0.171	0.911	0.004	0.734	1	147	0.393
3	0.488	0.238	0.222	0.882	0.056	10.762	1	146	0.001
4	0.488	0.238	0.217	0.885	0.000	0.001	1	145	0.982
5	0.489	0.240	0.213	0.887	0.002	0.305	1	144	0.581
6	0.493	0.243	0.211	0.888	0.003	0.609	1	143	0.436

TABLE 15 Path Coefficient for the impact of COVID-19 on family bedtime routines.

Model	Independent variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	0.000	0.074		0.000	1.000
	Impact of COVID-19 to family	0.422	0.075	0.422	5.656	0.000
2	(Constant)	0.000	0.074		0.000	1.000
	Impact of COVID-19 to family	0.414	0.075	0.414	5.516	0.000
	Number of children with ASD	0.064	0.075	0.064	0.857	0.393
3	(Constant)	0.000	0.072		0.000	1.000
	Impact of COVID-19 to family	0.393	0.073	0.393	5.375	0.000
	Number of children with ASD	0.076	0.073	0.076	1.040	0.300
	Number of children without ASD	0.238	0.073	0.238	3.281	0.001
4	(Constant)	0.000	0.072		0.000	1.000
	Impact of COVID-19 to family	0.393	0.074	0.393	5.292	0.000
	Number of children with ASD	0.076	0.073	0.076	1.035	0.302
	Number of children without ASD	0.238	0.075	0.238	3.175	0.002
	Age of children with ASD	0.002	0.075	0.002	0.023	0.982
5	(Constant)	0.000	0.072		0.000	1.000
	Impact of COVID-19 to family	0.395	0.075	0.395	5.303	0.000
	Number of children with ASD	0.079	0.073	0.079	1.071	0.286
	Number of children without ASD	0.232	0.076	0.232	3.052	0.003
	Age of children with ASD	0.002	0.075	0.002	0.023	0.981
	Gender of children with ASD	0.041	0.074	0.041	0.553	0.581
6	(Constant)	0.000	0.073		0.000	1.000
	Impact of COVID-19 to family	0.393	0.075	0.393	5.259	0.000
	Number of children with ASD	0.078	0.074	0.078	1.056	0.293
	Number of children without ASD	0.219	0.078	0.219	2.819	0.005
	Age of children with ASD	0.003	0.076	0.003	0.045	0.965
	Gender of children with ASD	0.039	0.074	0.039	0.531	0.597
	Severity of ASD symptoms	0.058	0.075	0.058	0.780	0.436

dietitians, teachers and therapists, to provide further insights regarding the eating behavior and routines of the children with ASD.

Implications for research and practice

The findings of the study indicate that it is necessary for support for children with ASD to be expanded and reconsidered during the spread of any pandemic. The following recommendations are made in this regard:

i) Parents, teachers, behavior analysts, psychologists, dieticians, or nutritionists and others associated with the welfare of persons with ASD in Saudi Arabia must take a range of measures to help them deal with the pandemic-related changes to their schedule. For instance, parents could be trained to provide behavioral support and reinforcement (24).

ii) Behavior analysts with dieticians and/or nutritionists could collaborate with parents to adapt or design interventions that can be implemented at home by either or both parents.

iii) The Saudi Ministry of Health and Ministry of Education could initiate programs to oversee the training of parents and other caretakers of children with ASD during the pandemic and/or lockdown and promote the use of online interventions to support children of different age groups.

iv) The Ministry of Health and Ministry of Education could also facilitate the development of more virtual helplines to ensure that all parents of children with ASD can access varied sources of assistance such as behavior analysts, dieticians, and nutritionists.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material. Further inquiries can be directed to the corresponding author.

Ethics statement

This study was carried out in accordance with the Declaration of Helsinki and with the approval of the the Applied Medical Science committee at University of Taibah no, 2020/52/201/CLN. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MA: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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EDITED BY
Michaela DuBay,
University of Virginia, United States

REVIEWED BY
Daniel Matos,
Universidade Ceuma, Brazil
Antonio Javier Nakhal Akel,
Sapienza University of Rome, Italy

*CORRESPONDENCE
A. N. Bhat
✉ abhat@udel.edu

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Demographic differences in access to health/therapeutic services over first year of the pandemic: a SPARK COVID-19 impact survey analysis

J.-M. Tsai[1,2] and A. N. Bhat[1,2,3,4]*

[1]Department of Physical Therapy, University of Delaware, Newark, DE, United States, [2]Interdisciplinary Neuroscience Graduate Program, University of Delaware, Newark, DE, United States, [3]Biomechanics & Movement Science Program, University of Delaware, Newark, DE, United States, [4]Department of Psychological & Brain Sciences, University of Delaware, Newark, DE, United States

Introduction: This analysis examined changes in services received and service recovery one-year post-pandemic compared to pre-pandemic levels in children with ASD aged between 19 months and 17 years in various subgroups based on factors such as age, income, race/ethnicity, geographic location, and sex.
Methods: An online, parent report survey was completed by the parents of children with ASD in the SPARK study cohort ($N = 6{,}393$). Descriptive statistics, chi-square analyses, and Spearman correlations were performed to study associations between various factors and service access, pre-pandemic and one-year, post-pandemic.
Results: One year after pandemic, the lag in service recovery in children with ASD was greatest for PT/OT services followed by SLT. ABA services only recovered in half of the subgroups. In contrast, SES fully recovered and MH and MED services superseded pre-pandemic levels. Across majority of the timepoints, younger children received more SLT, PT/OT, and ABA services whereas older children received more SES, MH, and MED services. Higher income families accessed more SES, SLT, and ABA whereas lower income families received more MH services. White families received less SLT compared to non-white families. Hispanic families received more SLT services compared to non-Hispanic families. Compared to rural families, urban families received more ABA services at baseline which also recovered one year after the pandemic. Certain counterintuitive findings may be attributed to home/remote schooling leading to reduced access to related services.
Conclusions: Future research and policy changes are needed to address the American healthcare vulnerabilities when serving children with ASD by enhancing the diversity of healthcare formats for continued service access during future pandemics and other similar crises.

KEYWORDS

autism spectrum disorder (ASD), COVID-19 pandemic, speech language therapy (SLT), physical/occupational therapy (PT/OT), applied behavior analysis (ABA), mental health (MH) services, medical (MED) services

1 Introduction

Autism Spectrum Disorder (ASD) affects 1 in every 36 children in the United States (1). Due to various core (social communication and restricted/repetitive behaviors) and co-occurring (sensorimotor, language, and cognitive) impairments of ASD (2–5) families and children often access a variety of health services from early childhood to adulthood (6–8). Children with ASD commonly receive special education (SES), occupational therapy (OT), physical therapy (PT), speech language therapy (SLT), applied behavioral analysis (ABA), mental health (MH), and medical (MED) services including prescription medications (6, 9, 10). Pre-pandemic, service receipt rates reported in the literature for children with ASD varied across studies with 85%–97% individuals receiving SES, 35%–80% receiving OT, 32%–35% receiving PT, 45%–71% receiving SLT, 21%–40% receiving ABA, 42%–46% receiving MH, and 48%–56% receiving MED services (6, 7, 9, 11–14). Although 74% of children with ASD benefit from a wide range of services in the school settings, there were still ~63% children seeking services outside of school (7, 15). SLT and PT/OT were most accessed services in school settings, whereas ABA, MH, and MED services were often accessed outside of school (7, 15, 16).

Various demographic factors, such as child age and family's socioeconomic status (SES), race, ethnicity, and geographic location (urban/rural) are associated with access to services in children with ASD and related disorders (7, 11–13). For instance, access to some services (e.g., SLT, PT/OT, and ABA) reduces with age (13); higher socioeconomic status (i.e., higher family income) is associated with greater use of SLT, ABA, MED, SES and MH services (15–20); Hispanic children are less likely to receive SES, SLT, OT, and MED services compared to non-Hispanic children (17, 21–25). Last but not the least, children living in metropolitan areas (vs. rural areas) were found to have greater access to SLT and behavioral therapies (7, 16). These demographic inequities in service access were further tested during the recent COVID-19 pandemic.

The COVID-19 pandemic was marked by sudden school and facility closings due to strict lockdown throughout the US. Most healthcare services were negatively impacted, rendering significant and long-lasting disruptions of available services for children with developmental disabilities and their families (26–29). Jeste and colleagues reported 63%–70% of families lost various therapeutic services (26). Children with ASD had even more significant service disruptions. The study team at the Simons Foundation Powering Autism Research for Knowledge (SPARK) conducted online surveys in a large sample of parents and caregivers of children with ASD between April 2020 and July 2021. 78.5% families reported moderate to severe disruptions due to the pandemic (27, 28) 80% families reported disruptions to SES, 88% to SLT, 84% to PT/OT, and 77% to ABA services (27, 28). Younger children and children from low-income families faced greater service disruptions and significant parental stress due to pandemic-related loss in services (27, 28–31). Currently, there are limited data on how services recovered over the first year following the pandemic. Hence, we describe data from the SPARK COVID impact survey on how services recovered at the end of the first year of the pandemic (March 2021) compared to pre-pandemic service levels offered to children with ASD. In addition, we examine the variations in services received based on multiple demographic factors, such as age, family income, race/minority status, ethnicity, geographic location, and sex. Based on past literature, we hypothesize that younger children, children from racial/ethnic minorities, low-income families, and rural areas, will show differences in service recovery one-year post-pandemic compared to other demographic groups.

2 Methods

2.1 Participants

At the onset of the COVID-19 pandemic in March 2020 (timepoint 1 or T1) parents of children with ASD from the SPARK study completed the COVID-19 impact survey. These families were re-contacted at multiple additional timepoints in April 2020 (time point 2 or T2), August 2020 (time point 3 or T3), October 2020 (time point 4 or T4), March 2021 (time point 5 or T5), and July 2021(time point 6 or T6) to obtain data on their access to various health/therapeutic services (see Table 1). In this report, we focus on data related to service receipt in children and adolescents between 19 months and <18 years of age. For a multiplex family (i.e., family with more than one child with ASD), a single child was selected at random by the parent and their issues have been reported for all timepoints. Note that T1 data on service disruptions at the onset of the pandemic have already been analyzed and reported by White et al. (27) and Bhat (28).

2.2 SPARK original procedures and data access

Families in the US with one or more children with ASD were eligible to join the SPARK study, an ongoing nationwide study following the development of individuals with ASD. Participants had been recruited through a growing number of clinical sites

TABLE 1 SPARK study sample size over time based on inclusion/exclusion criteria.

Time of survey administration	March 2020 (T1)	April 2020 (T2)	August 2020 (T3)	November 2020 (T4)	March 2021 (T5)	July 2021 (T6)
Question about services received/access	Not asked; Disruptions reported in Bhat (28)	Pre-pandemic (Jan/Feb 2020)	During last 2 months	During last 2 months	During last 2 months	During last 2 months
Original dataset	9,249	4,461	3,620	3,274	2,885	2,501
Form completed	9,027	4,370	3,620	3,274	2,885	2,501
Age ≤18 years	7,889	3,742	3,059	2,786	2,428	2,052
SCQ score non-blank	7,796	3,697	3,020	2,749	2,394	2,025
SCQ score ≥ 12	6,393	3,184	2,617	2,391	2,082	1,756
Final dataset	6,393	3,184	2,617	2,391	2,082	1,756
Total excluded	2,856 (30.9%)	1,277 (28.6%)	1,003 (27.7%)	883 (27.0%)	803 (27.8%)	745 (29.8%)

across the country using a multi-pronged social media strategy (32). Families voluntarily signed up for this study to fill out multiple online questionnaires on the SPARK website. This research team signed up for the SPARK study to gained access to the COVID-19 impact survey data and other demographic, medical, and clinical/developmental surveys completed by the participating families. This secondary data analysis was part of an exempt protocol approved by the University of Delaware Human Subjects Review Board (Protocol #: 1794596).

2.3 SPARK forms and measures

The SPARK COVID-19 impact survey asked families to report services received by their children and adolescents with ASD over the course of the pandemic including special education (SE), speech and language therapy (SLT), physical and occupational therapy (PT/OT), Applied Behavioral Analysis (ABA), Mental Health Services (MH), and medical services (MED). Note that the first data point from March 2020 (T1) only asked about service disruptions following the pandemic and these data have been reported in reference 28; hence, not discussed here.

In April 2020 or T2, parents were asked to recall the following, "Thinking back to January 2020, was your child regularly receiving the following service: ______", for example, SES or SLT, and so on (Response: Yes = 1, No = 0, Missing Data = 888); hence, timepoint 2 or T2 provided data on pre-pandemic service levels. At 4 timepoints, August 2020 (T3), November 2020 (T4), March 2021 (T5) and July 2021 (T6), the following question was asked, "In the past 2 months, has the subject received the following service: _______", for example, SES, SLT, and so on (Response: Yes = 1, No = 0).

The SPARK team also asked participating families to complete the basic medical screening form, the individual data form, and the Social Communication Questionnaire (SCQ). The basic medical screening form includes demographic information, birth history, professional diagnosis of ASD and other disorders, as well as other general medical conditions. The individual data form provides details on whether there is a presence of a cognitive impairment whether there is an Individualized Education Plan (IEP) for the child, and whether the child receives ASD services. Lastly, the Social Communication Questionnaire—Lifetime (SCQ) is a widely used parent questionnaire (Yes/No format) to screen for autistic traits in children above 4 years of age with a mental age of at least 2 years (33). A total SCQ score of >12 is indicative of a social communication delay and the child has a greater likelihood of being on the autism spectrum. The 12-point cut-off is a research recommended, more sensitive cut-off score (34–37). However, the timepoint T6, reflected service levels after summer school closings in July 2021; for this reason, we will focus on comparing timepoints T2 (pre-pandemic) and T5 (March 2021, 1 year after the pandemic). T5 was the latest timepoint during the school year when regular services were offered.

Percent services received at any given timepoint was the proportion of families receiving a particular service—SES, SLT, PT/OT, ABA, MH, or MED.

2.3.1 Service recovery

We defined full service recovery at any given timepoint, if the service was ≥85% of the percent service receipt at baseline/pre-pandemic. Note that small differences are not being considered as true because this is a cross-sectional analysis and services may differ due to differences unique to the respondents at each timepoint. Percent service recovery was calculated as the percentage of services received by a given subgroup at timepoint 5 (T5%) divided by the percentage of services received, pre-pandemic (T2%), multiplied by 100.

2.4 Inclusion/exclusion criteria

Table 1 lists the exclusion criteria in the first column as well as the basis for data exclusion/filtering. Out of the originally contacted families ($N = 9{,}249$), we only included those who completed the COVID-19 survey and who reported their child being younger than 18 years; which results in a sample of 7,889. We limited the sample to under 18 years in order to assess children who have access to IDEA-based services such as PT, OT, SLT; which is often provided to school-age children and not adults. Furthermore, only participants who completed the SCQ and met the SCQ cut-off of ≥12; often used to screen for ASD in large-scale studies (34, 35); which resulted in a final sample of 6,393.

Demographics of the final sample are presented in Table 2. Key demographics for this sample are as follows: ∼81% are males, ∼69% are Caucasian, ∼18% are multi-racial, 16% are Hispanics, there is a fairly equal distribution of income from ≤20K to ≥161K USD (6%–12%), ∼67% are from urban areas, and there is a fairly equal distribution of age from 3 to 18 years (i.e., 15%–24%) with ∼1.4% belonging to <3 years of age. Most of the missing data was for information on geographic location (∼21%), income (∼11%), and race (∼4%).

2.5 Statistical analysis

Statistical analyses were conducted using JMP Pro 16.0 (JMP, Inc). Proportion of different services received were compared across various demographic factors of sex, age, minority status, ethnicity, geographic location, socioeconomic status using chi-square analyses. Spearman correlation coefficients were used to examine associations between services received and various aforementioned factors. Statistical significance was set at $p < 0.05$. Bonferroni corrections were used when multiple comparisons/correlations were performed.

3 Results

3.1 Overall services received

As shown in Figure 1, pre-pandemic (T2), 61.1% children and adolescents received SES, 60.2% received SLT, 47.1% received PT/OT, 36.6% received ABA, 24.6% received MH and 14.0% received MED services. At the onset of the pandemic in March

TABLE 2 SPARK study demographic information for the sample.

N	6,393
Sex	Female: 1,235 (19.3%), Male: 5,158 (80.7%)
Minority status	White (includes families with at least one white parent): 5,464 (85.5%), Non-white: 659 (10.3%), Missing: 270 (4.2%)
Race	More than one: 1,182 (18.5%), Asian: 104 (1.6%), African American: 262 (4.1%), Native American: 23 (0.36%), Native Hawaiian: 5 (0.08%), Other: 120 (1.9%), White: 4,427 (69.2%), Missing: 270 (4.2%)
Ethnicity	Not Hispanic: 5,350 (83.7%) Hispanic: 1,043 (16.3%)
Annual household income [$]	≤20K: 627 (9.8%), 21K–35K: 782 (12.2%), 36K–50K: 729 (11.4%), 51K–65K: 608 (9.5%), 66K–80K: 667 (10.4%), 81K–100K: 667 (10.4%), 101K–130K: 657 (10.3%), 131K–160K: 362 (5.7%), ≥161K: 576 (9.0%), Missing: 718 (11.2%)
Geographic location	*Urban* [Large Central Metro: 1,121 (17.5%), Large Fringe Metro: 1,543 (24.1%), Medium Metro: 1,079 (16.9%), Small Metro: 543 (8.5%)], *Rural* [Micropolitan: 462 (7.2%), Noncore: 294 (4.6%)], Missing: 1,351 (21.1%)
Age A [Years]	$A \leq 3$: 89 (1.4%), $3 < A \leq 6$: 1,136 (17.8%), $6 < A \leq 9$: 1,548 (24.2%), $9 < A \leq 12$: 1,447 (22.6%), $12 < A \leq 15$: 1,236 (19.3%), $15 < A \leq 18$: 937 (14.7%)

2020, most services were significantly reduced or came to a halt. Even by August 2020 (T3), based on trends shown in Figure 1 compared to pre-pandemic levels, school-based services such as SES, SLT, PT/OT, and ABA were substantially lower in receipt, and recovered gradually by March 2021 (T5). Note that services reduced slightly more in July 2021 (T6) due to summer time school closures.

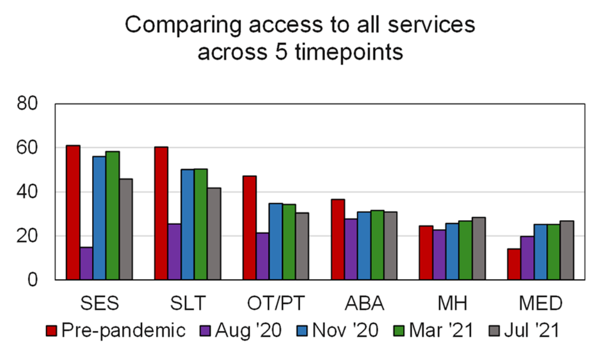

FIGURE 1
Percent of services received at various timepoints, pre-pandemic to July 2021. The Y-axis indicates % services received; the X-axis shows the various service types.

3.2 Variations in services received based on age

Figure 2 shows the comparisons of % service receipt between pre-pandemic baseline and 1 year-post-pandemic for each subgroup, based on age as well as various demographic factors. Table 3 shows the final % service recovery value for each subgroup as defined in section 2.3.1. As shown in Figure 2 and Table 3 for service recovery and Figure 3 on age-related differences in percent services received, for most time points, SLT, PT/OT, and ABA are provided more to younger children than older children with ASD as seen by the lowering trends with age. SES was relatively equal across school ages; however, access to MH and MED services increased with age. Post-pandemic, service recovery by March 2021 was seen in most age groups for SES, MH, and MED services but not for SLT, PT/OT, and ABA. Note that for ABA services, only three out of six age groups fully recovered (0–3Y, 3–6Y, 12–15Y). In fact, MED services showed more systematic scaling up in service proportions with age.

3.3 Variations in services received based on income

As shown in Figure 2 and Table 3 for service recovery and Figure 4 for income-based service proportions across multiple timepoints, SES, SLT, and ABA were accessed more by higher income families whereas lower income families accessed MH and MED services more. Post-pandemic, service recovery by March 2021 was seen in most income groups for SES, MH, and MED services but not for SLT, PT/OT, and ABA. As shown in Figure 2 and Tables 3, 5 out of 9 income groups did not fully recover in SLT services, 8 out of 9 income groups did not fully recover PT/OT services, and 4 out of 9 income groups did not fully recover in receiving ABA services. It must be noted that post-pandemic, access to MED services increased for all income groups.

3.4 Variations in services received based on minority status

As shown in Figure 2 and Table 3 for service recovery and Figure 5 for services received by minority status across multiple timepoints, SLT, OT/PT and ABA services were accessed more by non-white families than white families. In contrast, MH and MED services were accessed more by white families than non-white families. As shown in Figure 2 and Table 3, post-pandemic service recovery by March 2021, was seen in both groups (non-white and white) for MH and MED services but did not occur for PT/OT services. SES recovered for white families whereas SLT and ABA services recovered for non-white families.

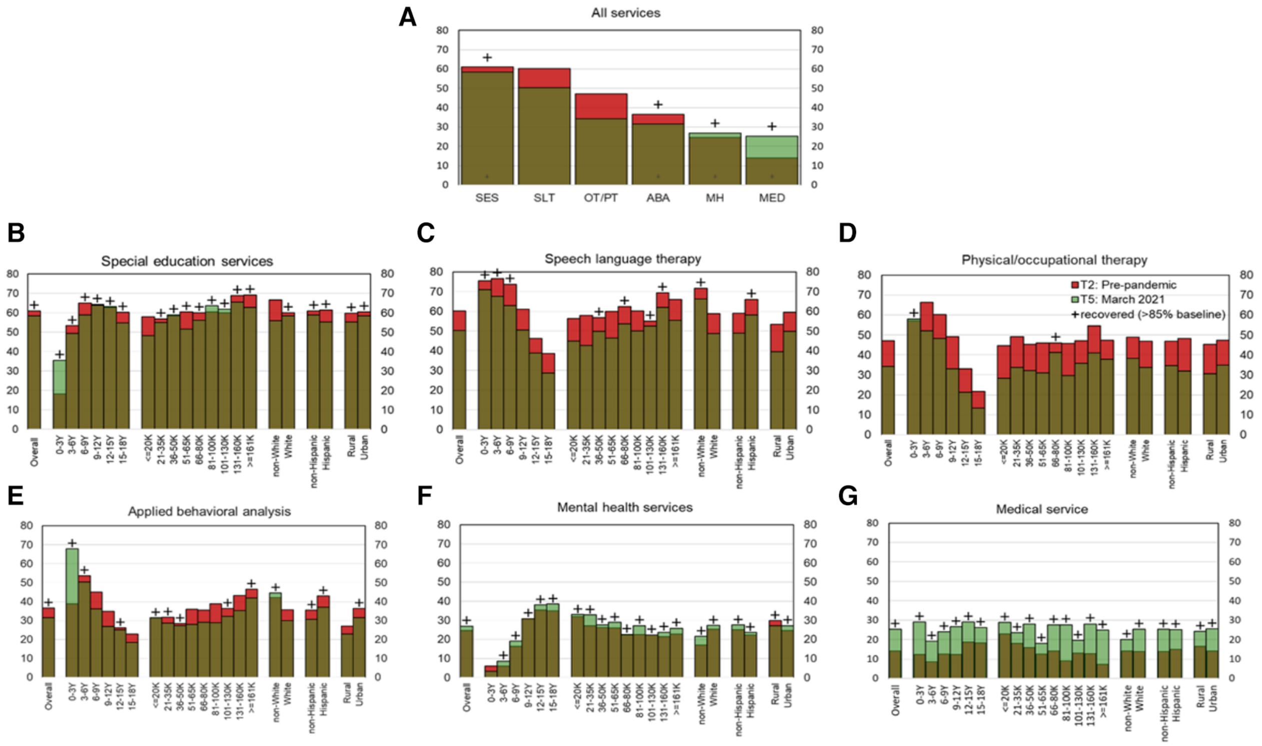

FIGURE 2
Service Recovery for the entire sample and for subgroups based on various demographic factors, is shown in (A) for all services, (B) for SES, (C) for SLT, (D) for PT/OT, (E) for ABA, (F) for MH, and (G) for MED services. Red bars indicate lag in service recovery and green bars indicate services surpassing pre-pandemic levels. The Y-axes in all panels shows percent service received. The X-axis in (A) indicates various service types and the X-axes in (B-G) indicate subgroups based on various demographic factors.

TABLE 3 Service recovery.

Services received/factors	Sub-group	SES	SLT	PT/OT	ABA	MH	MED
Age group	0–3 Years	193.2%	94.0%	101.6%	174.7%	52.7%	237.1%
	3–6 Years	92.6%	88.4%	78.4%	93.9%	145.9%	221.8%
	6–9 Years	90.6%	85.3%	80.0%	80.4%	115.7%	190.3%
	9–12 Years	99.3%	82.8%	67.1%	76.7%	100.3%	215.6%
	12–15 Years	100.6%	83.7%	64.5%	96.2%	107.4%	156.3%
	15–18 Years	91.0%	74.6%	60.7%	80.7%	110.4%	142.5%
Income level	<=$20K	83.1%	79.9%	63.4%	100.5%	103.3%	126.3%
	$21–35K	96.7%	73.8%	68.3%	90.5%	121.0%	130.5%
	$36–50K	100.9%	87.6%	71.0%	95.7%	105.5%	176.6%
	$51–65K	85.1%	77.4%	67.2%	77.4%	111.6%	143.0%
	$66–80K	93.4%	86.4%	89.6%	81.9%	100.9%	196.0%
	$81–100K	104.9%	83.2%	65.0%	74.3%	120.4%	303.8%
	$101–130K	103.0%	95.4%	76.2%	88.5%	99.5%	150.6%
	$131–160K	94.9%	89.0%	75.2%	81.4%	111.0%	218.6%
	>=$161K	90.5%	84.1%	79.6%	89.9%	113.3%	337.6%
Minority status	White	97.2%	82.8%	72.0%	83.8%	107.8%	183.0%
	Non-White	83.8%	92.3%	78.0%	106.2%	126.9%	143.6%
Ethnicity	Non-Hispanic	96.6%	82.8%	73.9%	86.2%	110.0%	182.5%
	Hispanic	90.1%	87.8%	66.2%	86.0%	105.8%	169.1%
Geographic location	Urban	96.5%	83.6%	73.4%	86.5%	110.1%	181.7%
	Rural	92.3%	73.9%	67.4%	84.3%	91.1%	147.3%
Sex	Male	94.3%	82.8%	71.1%	84.2%	109.4%	186.3%
	Female	100.5%	87.0%	78.8%	94.5%	108.7%	160.8%
Overall	Not applicable	95.6%	83.7%	72.7%	86.2%	109.4%	180.3%

SE, special education; SLT, speech and language therapy; PT/OT, physical and occupational therapy; ABA, applied behavior analysis; MH, mental health; MED, medical. Gray shading indicates the subgroup did not show service recovery one-year post-pandemic (T5) vs. pre-pandemic (T2). Percent service recovery was calculated as the percentage of services received by a given subgroup at one-year post-pandemic (T5) compared to the same at pre-pandemic baseline (T2) multiplied by 100.

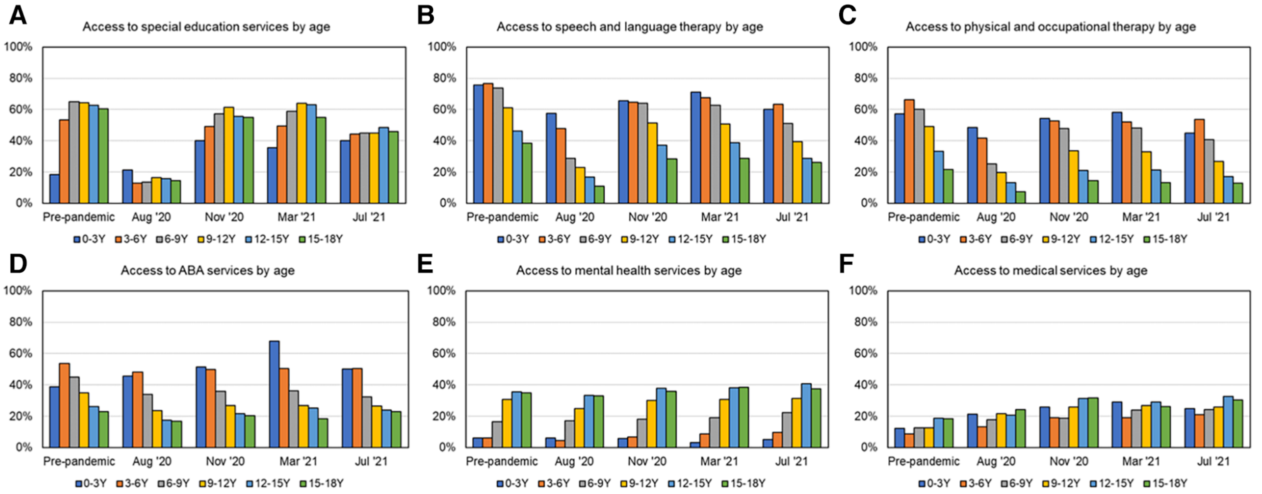

FIGURE 3
Percent services received as a function of age across timepoints over the first year of the pandemic, as shown in (A) for SES, (B) for SLT, (C) for PT/OT, (D) for ABA, (E) for MH, and (F) for MED services.

3.5 Variations in services received based on ethnicity

As shown in Figure 2 and Table 3 on service recovery and Figure 6 for services received based on ethnicity, across multiple timepoints, Hispanic families received more SLT and ABA services, compared to non-Hispanic families whereas non-Hispanic families received more MH services compared to Hispanic families. As shown in Figure 2 and Table 3, post-pandemic, service recovery for Hispanic families was seen for the majority of services except for PT/OT services whereas non-Hispanic families had full service recovery for most services except SLT and PT/OT services.

3.6 Variations based on geographic location and sex

As shown in Figures 2, 7, 8 and Table 3 at most time points, urban families received more SES, SLT, PT/OT, and ABA; whereas rural families received slightly more MH and MED services. As shown in Figure 2 and Table 3, post-pandemic service recovery was seen in majority of services for both urban and rural families; except SLT, PT/OT, and ABA services. SLT and PT/OT services did not recover for either geographic location groups. ABA recovered in urban but not the rural families. SES, MH, and MED services recovered in both groups based on location. Finally, there

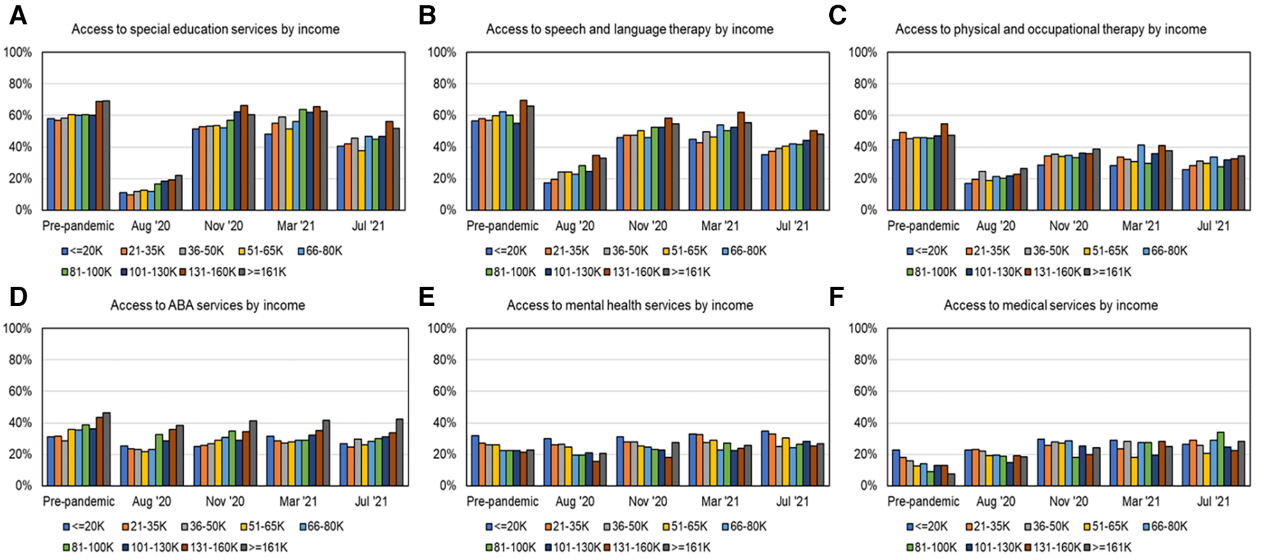

FIGURE 4
Percent services received as a function of income across timepoints over the first year of the pandemic, as shown in (A) for SES, (B) for SLT, (C) for PT/OT, (D) for ABA, (E) for MH, and (F) for MED services.

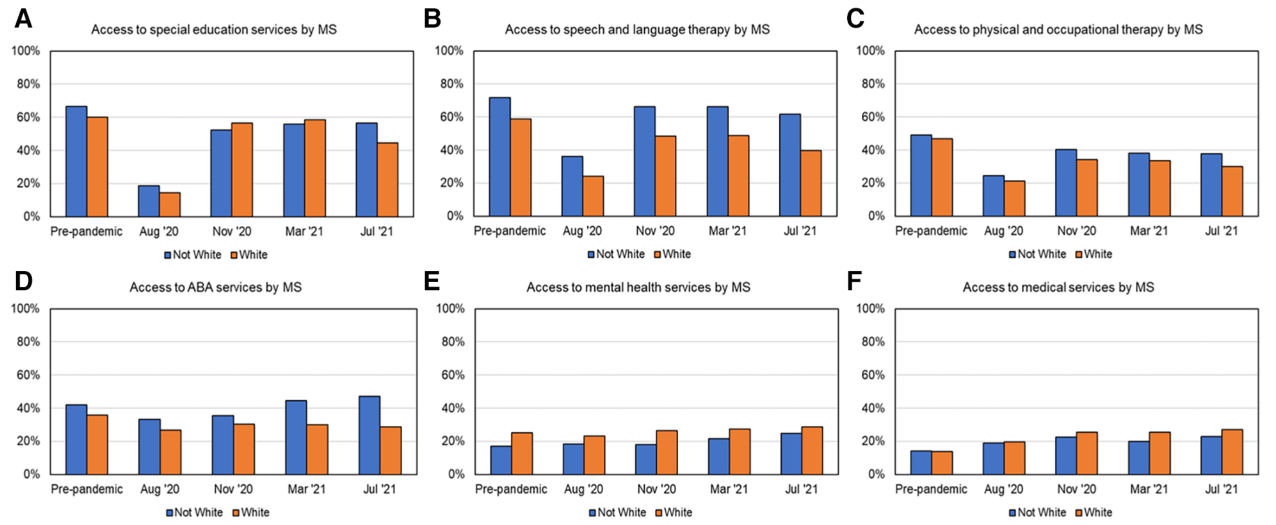

FIGURE 5
Percent services received as a function of minority status across timepoints over the first year of the pandemic, as shown in (A) for SES, (B) for SLT, (C) for PT/OT, (D) for ABA, (E) for MH, and (F) for MED services.

were sex-based differences in service recovery with males showing less recovery than females for SLT and ABA services and both groups not showing recovery for PT/OT services.

3.7 Chi-square analysis to examine service variations based on demographic factors

This analysis examined % service receipt at 1-year post-pandemic (T5%), compared to pre-pandemic baseline (T2%), and how that differed across demographic subgroups. Only T2 and T5 timepoints were compared as both timepoints occur during the school year. In addition, T2 was the earliest timepoint with service receipt data and T5 was the latest timepoint within the 1-year period. As shown in Figure 2 and Table 3 on service recovery and Table 4 on chi-square analyses indicated that access to multiple services differed across various demographic factors except sex. Majority of services including SES, SLT, PT/OT, ABA, MH services differed between age groups (pre-pandemic or timepoint 2 and 1-year post-pandemic or timepoint 5), whereas MED services only differed between age groups at T2 (pre-pandemic). Pre-pandemic, younger children with ASD received more SLT, PT/OT, and ABA services and relatively less SES, MH, and MED services compared to older children. One year after the pandemic, these trends did not change except for access to MED services did not differ between age groups. Based on

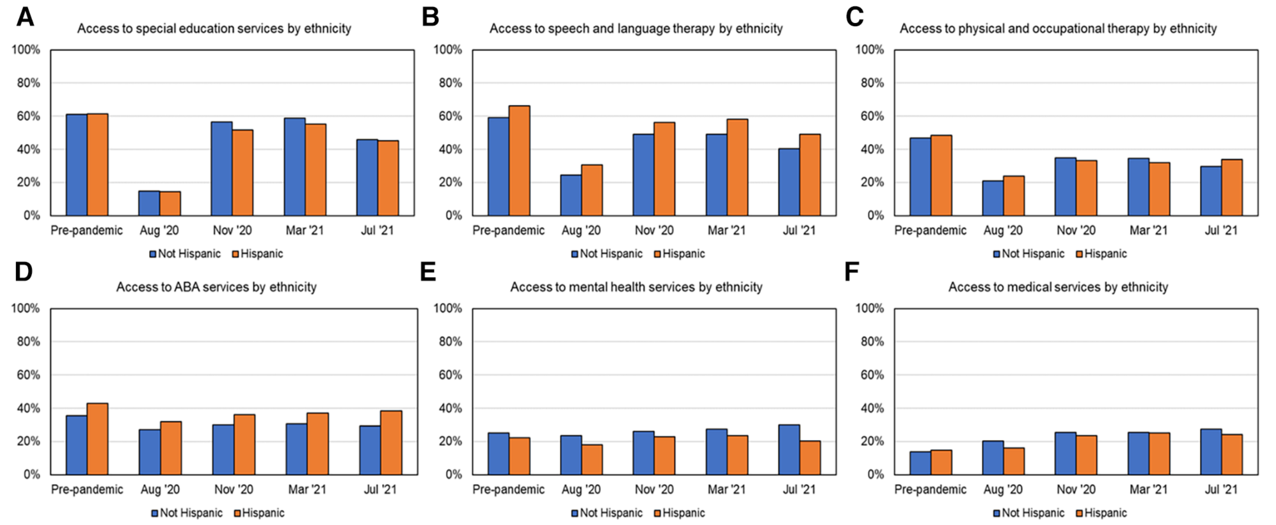

FIGURE 6
Access to services over time based on ethnicity, as shown in (A) for SES, (B) for SLT, (C) for PT/OT, (D) for ABA, (E) for MH, and (F) for MED services.

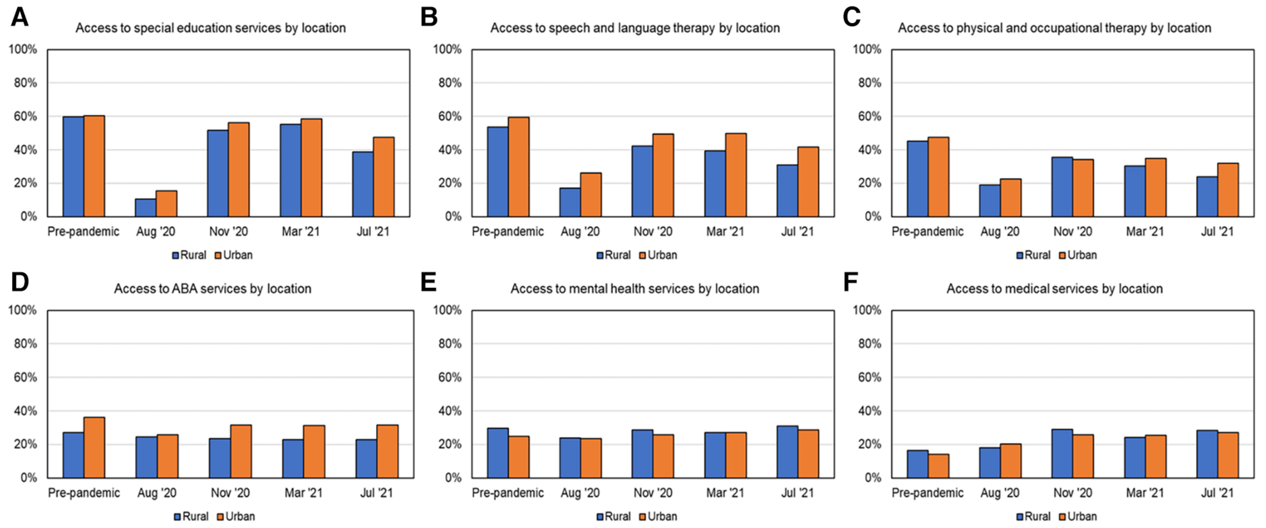

FIGURE 7
Access to services over time based on location, as shown in (A) for SES, (B) for SLT, (C) for PT/OT, (D) for ABA, (E) for MH, and (F) for MED services.

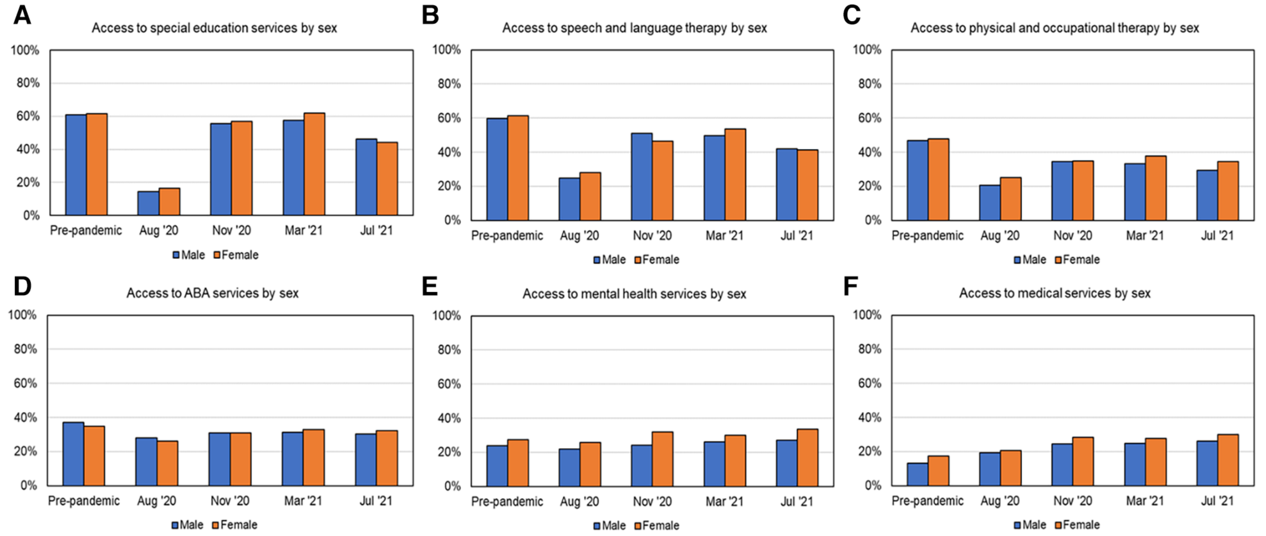

FIGURE 8
Access to services over time based on sex, as shown in (A) for SES, (B) for SLT, (C) for PT/OT, (D) for ABA, (E) for MH, and (F) for MED services.

income levels, pre-pandemic, higher income families accessed more ABA and less MED services compared to lower income families. However, these differences were not seen one year after the pandemic. Based on minority status, pre-pandemic, non-white families accessed more SLT services but fewer MH services compared to white families. One year after pandemic, non-white families continued to access more SLT and received more ABA services compared to white families. Based on ethnicity, one year after the pandemic, Hispanic families accessed more SLT services compared to non-Hispanic families. Based on geographic location, pre-pandemic, urban families accessed more ABA services but less MH services compared to rural families. One-year post-pandemic, urban families continued to access more SLT and ABA services compared to rural families. The non-significant results indicate that there was no significant difference in % service receipt between subgroups based on any given demographic factors. For exmaple, there were no sex-based differences in services received at either time points.

3.8 Correlations between various demographic factors and services received

Spearman correlations indicated that child's age, family income, minority status, ethnicity, and geographic location were significantly associated with % services received, as shown in

TABLE 4 Chi-squared values for services received (columns 3–8) in groups based on 6 demographic variables (rows 2–7) pre-pandemic (T2, first entry in each data cell) and march 2021 (T5, 12 months after pandemic onset—second entry in each data cell). Chi-squared values for *p* values less than adjusted alpha values are highlighted in yellow.

Services received/factors	Time point	SES	SLT	PT/OT	ABA	MH	MED
Age group	T2	119	220.4	269.1	119.2	316.6	52.03
	T5	29.46	166.9	205.9	116.5	149.7	NS
Income level	T2	NS	NS	NS	28.45	NS	53.24
	T5	NS	NS	NS	NS	NS	NS
Minority status	T2	NS	11.59	NS	NS	15.84	NS
	T5	NS	22.84	NS	17.38	NS	NS
Ethnicity	T2	NS	NS	NS	NS	NS	NS
	T5	NS	9.048	NS	NS	NS	NS
Geographic location	T2	NS	NS	NS	10.43	6.3	NS
	T5	NS	7.73	NS	6.6	NS	NS
Sex	T2	NS	NS	NS	NS	NS	NS
	T5	NS	NS	NS	NS	NS	NS

NS, not significant; SE, special education; PT/OT, physical and occupational therapy; SLT, speech and language therapy; ABA, applied behavior analysis; MH, mental health; MED, medical.

TABLE 5 Spearman correlations between demographic variables (rows 2–7) and parent-reported impact of COVID-19 on services received (columns 3–8) for pre-pandemic data (first entry in each data cell) and data from march 2021 (12 months after pandemic onset—second entry in each data cell). Correlations with *p* values <0.0014 after Bonferroni corrections are highlighted in yellow; and correlations with *p*-values >0.0014 and <0.01 are highlighted in green.

Services received/factors	Time point	SES	SLT	PT/OT	ABA	MH	MED
Age group	T2	0.157	−0.272	−0.297	−0.2	0.313	0.13
	T5	NS	−0.278	−0.304	−0.224	0.246	NS
Income level	T2	0.054	NS	NS	0.094	−0.082	−0.128
	T5	0.087	0.085	NS	0.067	−0.065	NS
Minority status	T2	NS	−0.064	NS	NS	0.075	NS
	T5	NS	−0.105	NS	−0.095	NS	NS
Ethnicity	T2	NS	NS	NS	NS	NS	NS
	T5	NS	0.066	NS	NS	NS	NS
Geographic location	T2	NS	NS	NS	0.069	NS	NS
	T5	NS	0.069	NS	NS	NS	NS
Sex	T2	NS	NS	NS	NS	NS	NS
	T5	NS	NS	NS	NS	NS	NS

NS, not significant; SE, special education; PT/OT, physical and occupational therapy; SLT, speech and language therapy; ABA, applied behavior analysis; MH, mental health; MED, medical.

Table 5 and Figures 3–8, albeit the correlation coefficients were relatively small. Pre-pandemic, child's age negatively correlated with access to SLT, PT/OT, and ABA services (i.e., younger children received more of these services), but positively correlated with access to SES, MH and MED (i.e., older children received more of these services). Similar trends were observed one year after the pandemic except for SES and MED services. Pre-pandemic, family income positively correlated with access to SES and ABA services (i.e., higher income families accessed more SES and ABA services) and negatively correlated with MH and MED services (i.e., lower income families accessed more MH and MED services). Interestingly, one year after the pandemic, positive correlations were seen between family income and receipt of multiple services including SES, SLT, and ABA services (i.e., higher income families accessed more of these services) and negatively correlated with MH services (i.e., lower income families accessed more MH services). Pre-pandemic, minority status negatively correlated with access to SLT services (i.e., non-white families accessed more SLT) but positively correlated with access to MH services (i.e., white families accessed more MH services). Post-pandemic, SLT and ABA trends were similar to pre-pandemic trends (i.e., non-white families accessed more SLT and ABA). While there were no differences pre-pandemic, one year after the pandemic, ethnicity was positively associated with SLT receipt (i.e., Hispanic families received more SLT services than non-Hispanic families). Geographic location was positively correlated with access to ABA pre-pandemic and access to SLT post-pandemic (i.e., living in urban area was associated with higher ABA and SLT receipt). Sex did not correlate with access to any service at either timepoints.

4 Discussion

4.1 Overall results

This analysis examined the recovery in services received by children with ASD using an online parent survey completed by the SPARK cohort in the first year of the COVID-19 pandemic. The data extracted from the SPARK cohort is a fairly well-represented sample of children with ASD across the United States. Overall, SES had fully recovered one year after the pandemic onset, and MH and MED services had superseded the baseline levels, while SLT, PT/OT and ABA services had not fully recovered. Specifically, ABA services had recovered for some but not all subgroups. Among demographic factors, age, income, minority status, ethnicity, and geographic location were associated with service access pre/post-pandemic. Pre-pandemic, age was associated with all services, with younger children receiving more SLT, PT/OT, and ABA and older children receiving more SES, MH, and MED services; however, post-pandemic, these trends continued for SLT, PT/OT, ABA, and MH only. In terms of service recovery, service access to SLT, PT/OT, and ABA recovered more in younger children compared to older children. In general, families with higher income received more SES, SLT, and ABA and lower income families accessed more MH and MED services. One year after the pandemic, most income groups recovered in their access to SES, MH, and MED services but access to SLT, PT/OT, and ABA services did not recover. Nevertheless, SES, SLT, and ABA services continued to be greater for higher income families compared to lower income families whereas lower income families accessed more MH services. While white and non-white families showed service recovery for MH and MED services; neither showed recovery in access to PT/OT services. SES recovered more for white families whereas SLT and ABA services recovered more for non-white families. While there were no pre-pandemic differences, Hispanic families received more SLT and had greater recovery compared to non-Hispanic families, post-pandemic. Compared to rural families, urban families received more ABA in general and had ABA service recovery after one year but this was not seen in the rural families. Lastly, one year following the pandemic, PT/OT services had not fully recovered in any of the subgroups based on age, income levels, race/ethnicity, location, or sex. The overall findings indicated that health inequities across various subgroups either remained the same, exacerbated or reversed during the pandemic.

4.2 Recovery across service types

In terms of school-based services, before the pandemic, access to SES and SLT was greater than PT/OT, and then ABA services. One year after the pandemic, in March 2021, SES and ABA seemed to have recovered but SLT and PT/OT services had not reached pre-pandemic levels. Specifically, PT/OT services significantly lagged in recovery for the majority of subgroups. ABA services only lagged in recovery for about half of the subgroups. Pre-pandemic, compared to school-based services such as SES, SLT, PT/OT fewer children with ASD received MH and MED services. However, one-year post-pandemic, MH and MED services superseded their pre-pandemic levels. The rise in access to MH and MED services may be due to the worsening in children's ASD severity following the sudden loss in therapeutic services after prolonged lockdowns and social distancing policies. Another possible explanation is that MED and MH services were mainly provided through community clinics (outside of school settings) and hence, were less susceptible to school closures. After lockdowns subsided, community-based clinics may have recovered sooner than schools due to the small-scale nature of clinics (i.e., involved fewer clinicians or provided one-on-one services). It may also be that MH and MED services, are more prescription/conversation-based and require less hands-on interactions, and hence, are more amenable to shifting to telehealth formats. It is also possible that telehealth-based models of MED and MH services were established long before the COVID-19 pandemic for greater access to rural areas and were easily utilized during the pandemic due to preexisting infrastructure and functional insurance reimbursement policies (38–42). Similar to MED and MH services, telehealth-based, parent-mediated delivery ABA models were already being tested and developed before the pandemic and hence, the transition to telehealth ABA services was also accelerated by the COVID-19 pandemic (43–45). Hence, apart from the recovery in school-based ABA services, alternative formats may have restored ABA services in certain subgroups. Note that for certain subgroups (e.g., older children, rural families, white families, older children and middle-income groups) ABA services were still lagging in recovery one year after the pandemic.

The most prominent finding across all subgroups was the significant lag in service recovery in PT/OT services. Conventional PT/OT services, often utilize materials such as larger play equipment and spaces such as the school gym or clinic facilities. It also requires more hand-on-hand assistance from clinicians making it more challenging for PT/OT to transition to telehealth formats. In addition, PT/OT interventions are often provided to children with ASD needing significant support and screen-based therapies requiring attentional focus can be challenging for younger children as well as those needing more support. It is possible that these barriers reduced access to PT/OT services even one-year post-pandemic. However, recent clinical reports confirm that telehealth can be implemented by developing creative play activities using home-based supplies, by delivering supplies and training parents prior to session delivery (45, 46). Telehealth OT via parent-mediated coaching was also found to be highly acceptable for parents with children of ASD (47). However, there is a need for more research in the area of telehealth PT/OT services to identify effective ways to provide services to children with developmental disabilities, in general.

Before the pandemic, there was limited evidence for how SLT could be delivered through parent-implemented remote coaching in children with ASD. Sutherland et al. conducted a systematic review of 14 studies examining telehealth delivery of mental health counseling and ASD diagnosis/assessment efficacy and found their efficacy to be similar to that of face-to-face interaction models; however, they only reported one SLT intervention using a single case report (48). Similar to PT/OT, before the pandemic, children with ASD mainly received SLT services during their regular school day (7, 8, 49). While school-based services switched to remote formats, telehealth SLT was perhaps not easily adopted for multiple reasons. SLT heavily relies on the use of language and sound during treatment which made it more susceptible to technological issues such as poor audio-visual quality, internet connectivity and background noise, resulting in more implementation barriers. In addition, telehealth formats of SLT and PT/OT services require greater parental involvement for them to be meaningfully delivered to children needing more support who have attention difficulties. For all these reasons, transitioning SLT and PT/OT services to alternative formats may have been more challenging.

4.3 Differences in service recovery based on age

Younger children received more SLT, PT/OT, and ABA but less SES, MH, and MED services compared to older children. This fits with the literature reporting that younger children receive more therapy services (SLT, PT/OT, and ABA) which decline with age and instead older children/adolescents are more likely to receive MH and MED services compared to younger children (6, 7, 12). Hence, it is not surprising that service access of younger children was restored for the services that they most received pre-pandemic (i.e., SLT, PT/OT, and ABA). Early interventions through SLT, PT/OT, ABA are mandated by the IDEA law and therefore, younger children accessed more SLT, PT/OT and ABA than older children to meet their urgent developmental needs. It is also reported that older children/adolescents with ASD do not receive enough SLT and PT/OT (i.e., important for communication and functional skill development) resulting in significant unmet needs in many young adolescents and adults (6, 50, 51). In short, our findings indicated that older children/adolescents with ASD faced even greater service losses post-pandemic, as they were already facing unmet service needs related to SLT and PT/OT services before the pandemic.

In contrast, we also found increased use of MH and MED services in older children before and after the pandemic. This is consistent with the previous findings that older children (ages 15–17 years) use more individual counseling and group therapy than younger children (12). In addition, older youth with high-functioning ASD had greater MH and MED service needs such as mental health counseling, psychotherapy, and prescription medication use due co-occurring conditions that may develop with age, e.g., anxiety, attention deficit, depression, and other psychiatric conditions (5, 52, 53). Additionally, the social distancing requirements and drastic changes to daily routines/school schedules may have worsened children’s ASD severity and in turn increased their need for MH and MED services.

4.4 Differences in service recovery based on income

Past studies have reported that lower socioeconomic status is associated with a decreased likelihood of receiving special education services and ABA services (15–17) and that families with higher SES were more likely to enroll/advocate for their children to receive PT/OT and ABA services within or outside of school (21). Although our result of higher income families receiving fewer MH services compared to lower income families seems non-intuitive at the outset, it is possible that higher income families were less negatively impacted during the pandemic and did not seek out as many MH services. The finding of MED service receipt increasing across all income groups, was different from past studies. For example, Liptak et al. (18) and Lokhandwala et al. (19) found that families from lower SES reported reduced access to primary healthcare and ASD treatment services as well as lower rates of hospitalization/underutilization of services. It is possible that in general children with ASD were not receiving the required SES, PT/OT, and ABA as part of their regular school day and that may have worsened their child’s ASD symptoms and led to them to seeking more MED services.

4.5 Differences in service recovery based on race/ethnicity

One year after the pandemic, SLT services had not fully recovered in white families, whereas SES had not fully recovered for non-white families. Hispanic families received more SLT compared to non-Hispanic families. Lastly, PT/OT services did not recover for any of the subgroups based on race/ethnicity. Previous studies have reported that children with ASD from white families are known to receive critical MH services much earlier (54). However, our findings suggested white families received less SES, SLT, and ABA seems counterintuitive. We speculate that white families had more access and resources through homeschooling and were unable to access as many “related services” such as SLT and ABA that they previously received from public schools. In addition, post-pandemic concerns about getting COVID-19 may have prevented white families from accessing community or school-based services even as late as March 2021 as pediatric vaccines were unavailable at the time.

4.6 Differences in service recovery based on geographic location

We found that urban families received more SLT and ABA; whereas rural families received more MH services pre-pandemic. Post-pandemic service recovery was seen in majority of services for both urban and rural families; except SLT, PT/OT, and ABA services. ABA only fully recovered in urban families and PT/OT as well as SLT services did not recover for either subgroups. This fits with what we know from previous studies that children living in metropolitan (vs. rural areas) have greater access to SLT and ABA/behavioral therapies at schools and in the community (7, 16). This may have made it easier for urban family to recover, one-year post-pandemic. Rural families mainly access services through their public schools; which were either closed or not providing adequate services due to staff/teacher shortages and limited resources in adapting to telehealth interventions. Together, this may explain the slower service recovery in rural families, one-year post-pandemic.

4.7 Limitations, conclusions, and future directions

Through this analysis, we offer a historical record, of how children with ASD faced service loss and partial service recovery in the first year after the COVID-19 pandemic. Multiple demographic factors were associated with services received. Although this was a relatively larger, representative sample of children with ASD in the US, the proportion of certain minorities was lower—non-white (10%) and Hispanic (15%). In addition, this was a survey study requiring families to respond at multiple timepoints which in turn led to substantial missing data over time. While these results provide a historical record of service disruptions and recovery in the first year of the pandemic, they should be interpreted with caution for subgroups with smaller samples. Other child and parent-related factors could also affect service recovery following the pandemic and will be reported elsewhere. Lastly, the SPARK COVID-19 impact survey ended after the first year of the pandemic; hence, there is no record of how services evolved and bounced back to normalcy in the school year that followed; when COVID-19 vaccines became more available to the public.

In the first year of the pandemic, school and medical systems made substantial efforts to fully restore all therapeutic services and not just special education, mental health, and medical services; which mostly recovered; 1-year post-pandemic. However, PT/OT services showed the most lag in service recovery followed by SLT, and lastly ABA. In the future, more research is needed to study the feasibility, acceptability, and health outcomes using alternative formats of PT/OT and SLT services (telehealth-based, community-based, or home-based) as well as parent or aide-mediated interventions (as opposed only relying on in-person, school-based services). We also recommend families and insurance companies to continue accessing community-based/home-based services that can be covered through health insurance to fill intervention gaps that exist within school systems. Policymakers should enforce laws that support alternative therapeutic formats outside of school systems, including community clinics, home-based services, as well as telehealth services for children with ASD and other disabilities. The COVID-19 pandemic tested the strength of our health service systems, revealed the vulnerabilities of therapeutic services offered to children with ASD and other disabilities in the US, and indicate the urgent need for greater diversity in therapeutic service formats.

Data availability statement

Publicly available datasets were analyzed in this study. This data can be found here: https://base.sfari.org.

Ethics statement

The present study was a secondary data analysis conducted through a protocol exemption approved by the University of Delaware Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

JT: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal Analysis, Data curation. AB: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal Analysis, Data curation, Conceptualization.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Testing an online screening for autism in the COVID-19 pandemic: a psychometric study of the Q-CHAT-24 in Chilean toddlers

Gabriel Gatica-Bahamonde[1,2,3,4]*, Alejandra Mendez-Fadol[4,5], Francisca Sánchez-Sepúlveda[4], Constanza Peñailillo-Diaz[4], Robin van Kessel[1,3,6], Katarzyna Czabanowska[1] and Andres Roman-Urrestarazu[3,4,7]

[1]Department of International Health, Care and Public Health Research Institute (CAPHRI), Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, Netherlands, [2]Sección de Psiquiatría del Niño y del Adolescente, División de Neurociencias, Facultad de Medicina, Pontificia Universidad Católica de Chile, Santiago, Chile, [3]Mental Health, Policy and Economics Group, Department of Psychiatry, University of Cambridge, Cambridge, United Kingdom, [4]Tremün Lab, Corporación Tremün, Villarrica, Chile, [5]Departamento de Pediatría, Facultad de Medicina, Universidad de La Frontera, Temuco, Chile, [6]LSE Health, Department of Health Policy, London School of Economics and Political Science, London, United Kingdom, [7]Institute of Public Health, University of Cambridge, Cambridge, United Kingdom

Background: The aim of this study was to examine some psychometric characteristics of the Chilean-adapted version of the Quantitative Checklist for Autism in Toddlers (Q-CHAT-24) (24) in a group of unselected children (community sample). This version was administered remotely through an online version during the pandemic period to caregivers of children, aged 18–24 months, registered in four primary care polyclinics of the Health Service Araucanía Sur, Chile.

Methods: An intentional non-probabilistic sampling was used. Three hundred and thirteen toddlers were examined. Participants completed an online version of the Q-CHAT-24 which was disseminated through the REDCap platform. Evidence of reliability through internal consistency and evidence of predictive validity through ROC curve analysis were realized.

Results: The mean age of the children evaluated was 21.16 months. The Shapiro-Wilk test revealed that Q-CHAT-24 scores was normally distributed. 71 cases (23.12%) scored 38 points or more on the Q-CHAT-24, qualifying as Autistic Risk. 48 cases (15.63%) were confirmed as autistic through the ADOS-2 Module T. All items were positively correlated with Q-CHAT-24 total score. All items were positively correlated with Q-CHAT-24 total score. Internal consistency was acceptable for the Q-CHAT-24 (Cronbach´s α=0.78). The internal consistencies were analyzed for the Q-CHAT-24 Factors, and they were good for factor 1 "Communication and Social Interaction" (Cronbach´s α=0.85) and acceptable for factor 2 "Restrictive and Repetitive Patterns" (Cronbach´s α=0.74). Receiver operating characteristic (ROC) curve analyses were performed.

EDITED BY
Cecilia Montiel Nava,
The University of Texas Rio Grande Valley,
United States

REVIEWED BY
Magdalena Budisteanu,
Prof. Dr. Alexandru Obregia Psychiatry Hospital, Romania
Katherine Stavropoulos,
University of California, Riverside,
United States

*CORRESPONDENCE
Gabriel Gatica-Bahamonde
gabriel.gatica@uc.cl

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The AUC values were 0.93 with statistical significance (p<0.01). For the cut-off point of 38, the Sensitivity, Specificity and Youden index values were 0.89, 0.8 and 0.7, respectively. The Positive Predictive Value (PPV) was 86% and the Negative Predictive Value (NPV) was 85%.

Conclusions: In accordance with the objectives of this study, evidence of reliability and predictive validity was demonstrated for the Q-CHAT-24 in this Chilean population. More importantly, this study provides Sensitivity and Specificity data for a remote application version of an autism screening tool already validated in Chile. The implications of this have to do with the possibility of establishing a remote assessment system for children at risk of autism on a population scale.

KEYWORDS

autism spectrum disorder, early detection, online screening, screening, COVID-19, Q-CHAT, autism, telehealth

1 Introduction

Autism Spectrum Disorders (ASD, hereafter ‘autism’) are a group of neurodevelopmental conditions characterized by persistent difficulties in communication and social interaction, and the presence of restricted and repetitive patterns of behavior, interests, and activities (1). Autism is of increasing epidemiological importance: recent studies show prevalence between 1.76% (UK) (2) and 2.77% (US) (3).

Early detection of signs of autism allows early referral to intervention programs (4). This is important because there is evidence that early management improves the prognosis and quality of life of children and their families (5, 6), that interventions are more effective at earlier ages (7) and that early intervention results in lower costs for the health care system (8).

Evidence shows that signs of autism can be detected early during the first and second years of life through caregiver’s self-report by screening tool (9). An autism screening tool is a brief assessment that is administered to detect those who exhibit traits of autism and are therefore at risk for the condition (10) and who can thus be referred to early intervention programs within a critical developmental period priced at 36 months of age (6). Evidence shows that early detection through screening reduces the time between diagnosis and initiation of intervention by up to 70% (11). Despite the above, a very small percentage of parents are alerted to their child’s developmental problems through the application of an autism-specific screening test (12) and a percentage between 30% and 50% of children with autism continue to be diagnosed after the age of 6 years (13).

With restrictions on face-to-face and in-person care, the COVID 19 pandemic posed a major challenge to the goal of early detection and diagnosis of autism, requiring rapid adaptation of child care services to the remote mode of care (14, 15). Brunt et al. (2023) (15) found that while all child populations had their assessment and diagnostic processes disrupted in the pandemic, there were glaring disparities for children with autism.

While prior to the pandemic there were studies showing the feasibility and preliminary accuracy of telemedicine early diagnosis methods (16), evidence for remote assessment methods is still limited. Corona et al. (2023) (17) evaluated the diagnosis concordance of autism between a face-to-face assessment and a remote assessment using ELE-ASD-PEDS (TAP) and the Screening Tool for Autism in Toddlers (STAT), in a sample of 144 children aged 17–36 months. The concordance between the face-to-face and remote assessments was 92%. Some of the factors that explained the diagnostic errors in the remote method were the younger age of the children and the better performance in the developmental assessment. Gibbs et al. (2021) (18) conducted a study investigating the acceptability of remote diagnostic procedures in the COVID-19 crisis. In general, caregivers and parents of children with autism felt welcomed in remote settings and their expectations of assessment were met, but the authors emphasized the need for a high structured assessment process. Colombo et al. (2022) (19) published a descriptive and preliminary analysis of a web platform (Web Italian Network for Autism Spectrum Disorder WIN4ASD) that used CHAT as a tool for early autism screening in a limited care setting.

Chile is a South American country with a population of approximately 19 million inhabitants (20), which despite being considered a high-income country, lives with significant health disparities (21). To address inequalities in the diagnosis and detection of autism, Chile has legislated a new autism law in 2023 that establishes a regulatory framework for the comprehensive care and protection of people with this condition, with the aim of improving their quality of life and promoting their social inclusion (22). The law makes explicit the centrality of early detection in the approach to the condition. A recent systematic review evaluated the tools validated in Chile for early detection of autism, finding only three screening tools (23). Among them is the Q-CHAT, a tool that has been translated, adapted, and validated in Chile by our team demonstrating evidence of Validity, Reliability and Sensitivity/Specificity suitable for use as population Screening (24, 25).

The Quantitative CHecklist for Autism in Toddlers, Q-CHAT (Allison et al., 2008) is an autism screening tool that conceptualizes the autism spectrum on a continuous scale, taking a dimensional approach to the identification of autistic traits (26–29). From a theoretical point of view, this proposal is consistent with the conceptual evolution of autism and with the quantitative nature of autistic traits as a continuum of symptoms and traits within the autism spectrum (30). The ability to dimensionally measure autistic traits using the Q-CHAT is supported by evidence showing that test scores are typically distributed across diverse populations studied (24, 26–28, 31, 32). In our study of adaptation and validation of the Q-CHAT in Chile (24), by means of an exploratory factor analysis we found a factor structure of 2 factors: a factor that groups the Socio-Communicative symptoms (Factor 1, "Communication and Social Interaction") and a Factor that groups the repetitive behaviors (Factor 2, "Restrictive and Repetitive Patterns"). This version of the Q-CHAT excluded by rational test analysis item 18, leaving a 24-item version, the Q-CHAT-24. In a recent report (33), cut-off scores for the Q-CHAT-24 were established according to the harmonized optimal levels of Sensitivity/Specificity and the Youden Index. The cut-off point was 38, with a Sensitivity of 0.93, Specificity of 0.81 and Youden index of 0.70.

The overall objective of this study was to examine some psychometric characteristics of the Chilean-adapted version of the Quantitative Checklist for Autism in Toddlers (Q-CHAT-24) (24) in a group of unselected children (community sample). This version was administered remotely through an online version during the pandemic period to caregivers of children, aged 18–24 months, registered in four primary care polyclinics of the Health Service Araucanía Sur, Chile.

2 Materials and methods

2.1 Participants

A descriptive correlational design was used for this study. The sampling technique was non-probabilistic intentional. All primary caregivers of children aged 18–24 months who attended or were contacted remotely (by video call) for developmental follow-up during the quarantines periods in which this study was conducted (October 2020 to September 2021), in four primary care clinics in the Araucanía region of Chile during the study period (n=854), were invited to participate. Three hundred and seven (36.6%) caregivers agreed to participate.

The inclusion criteria were a) aged between 18 and 24 months at the time of the assessment, b) attended face-to-face with the primary caregivers or were contacted remotely for routine developmental follow-up checks. Primary caregiver was defined as the adult(s) responsible for the daily care of the young child (34). Exclusion criteria were a) not being accompanied by the primary caregiver(s), and b) presenting a genetic or neurological condition incompatible with the identification of the behaviors assessed (for example: severe gait disturbance, cerebral palsy, among others).

2.2 Instruments

2.2.1 The Quantitative CHecklist for Autism in Toddlers Chilean version

In its original version (26) the Q-CHAT is a 25-item, parent- or caregiver-reporting scale designed as an autism screening instrument for children aged 18–24 months. The items are scored on a 5-point Likert-type scale (0–4), where higher scores indicate greater autistic traits. Each item is accompanied by a color illustration, which seeks to increase comprehensibility. Total Q-CHAT score >38 was established as the autism risk score.

For this research we used a culturally adapted version validated for Chile by our team (24). In this study we established evidence of concurrent validity with the M-CHAT-R/F, evidence of validity through adequate internal consistency (α=0.86) and established a 2-factor factor structure, excluding item 18 of the original Q-CHAT from the factor solution. A recent report (Gatica-Bahamonde, under review) established the optimal levels of Sensitivity/Specificity and Youden index (0.93/0.82; 0.76) for the 24-item Q-CHAT (Q-CHAT-24) using the cut-off point of 38 for a sample of Chilean preschoolers. This version was reproduced in its entirety and made available to researchers for subsequent dissemination through the REDCap online platform (35).

2.2.2 The autism diagnostic observatory, second version

This is a standardized, semi-structured assessment of communication, social interaction, interests, and imaginative play, which defines the level of concern in relation to a possible diagnosis of ASD. This instrument consists of a set of precise activities, in a standardized context, in which the examinator observes behaviors relevant to the diagnosis of ASD. In this study, we used the Module T which is designed for children under 30 months of age.

2.2.3 Socio-demographic questionnaire

A questionnaire constructed for this study was used, which seeks to collect sociodemographic data about the caregiver and his/her family, such as age, gender, marital status, years of schooling and socioeconomic level, among others.

2.3 Procedure

Between October 2020 and September 2021, all primary caregivers of children aged 18–24 months were invited to participate when they personally accompanied their children to developmental check-ups or when they were contacted remotely by phone or video call (depending on pandemic health conditions). Along with explaining the scope of the study, a link was sent to their mobile phones with access to the digital informed consent and to the REDCap platform where they could answer the Q-CHAT-24 and the socio-demographic questionnaire. When a caregiver agreed to answer the Q-CHAT-24, the results and the final score of their child were obtained immediately, together with indications regarding the steps to follow in case of obtaining a score of 37 or less (no suspected autism), they were instructed to follow their usual developmental controls. For scores of 38 or more (suspected autism), the indication was to wait to be contacted by the research team to start the study to confirm or exclude autism by medical assessment and the administration of ADOS-2 Module T. The study of suspected autism cases was conducted within three months of the Q-CHAT-24.

2.4 Ethical considerations

By signing (digitally) an informed consent, the free and voluntary participation, the confidentiality of data provided by the participants and the fact that they would be used only for research purposes were assured. This research was approved by the ethics committee of Araucanía Health Service, Chile.

2.5 Statistical analysis

The distribution of the total Q-CHAT scores was explored using the Shapiro Wilk (S-W) test. The results were contrasted with the distribution histogram and the standardized normal distribution probability plot (Q-Q Plot). As part of a rational item analysis, item-total correlations were examined using Pearson's *r* parametric analyses. Reliability was estimated by examining internal consistency using Cronbach's alpha for the total scale scores and separately for each of the factors previously found (24). As a measure of predictive validity, receiver operating characteristic (ROC) curves and area under the curve (AUC) with sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV) were calculated for the cut-off points. Optimal cut-off points were selected based on their utility for screening purposes, following the proposal of Stevanovic et al. (29, 36): sensitivity and specificity > 0.8, sensitivity ≥ specificity, and Youden´s index ≥ 0.70.

3 Results

3.1 Socio-demographic characteristics

The mean age of the children evaluated was 21.16 months (median=20, range 18–24, SD=4.03), where 54.0% (n=169) were males. 78.2% (n=245) lived in urban sectors and 93.0% of the children belonged to families that had incomes below the 75th percentile of Chilean households, equivalent to less than US$1,140 (37). The mean age of caregivers was 30.0 years (median=30, range 18–60, SD=6.8). Of the caregivers who responded to the Q-CHAT, 93.5% (n=287) were mothers, 6.2% (n=19) were fathers, and 0.3% (n=1) were other caregivers. 78.8% (n=241) of the caregivers had 12 or more years of schooling.

Table 1 summarizes the socio-demographic characteristics of the sample.

3.2 Q-CHAT-24 total scores distribution, item score distribution and item analysis

For the Q-CHAT-24 the mean score for the whole sample analyzed was 30.62 (range 6–69, SD=11.1). The Shapiro-Wilk test revealed that the scores were normally distributed (S-W (307) =0.98, p<0.001) (Figure 1).

When analyzing scores by gender, the male Q-CHAT-24 mean score of 31.6 (SD=10.81, range 8–59) was higher than the female mean score of 27.98 (SD=9.71, range 6–63). These differences were statistically significant between the two groups (t(305) =2.44, p=0.01).

As part of a rational analysis of the Q-CHAT-24 items, an Item-Total correlation analysis (correlation between the Score of each item and the Total Score without considering the item to be analyzed) was performed. Each of the Q-CHAT-24 items was positively correlated with the Q-CHAT-24 Total Score. The item-total correlation was satisfactory (0.5>r>0.2) for most items, except for item 3 (r<0.2). The item-total analysis is shown in Table 2.

3.3 Q-CHAT-24 reliability

Internal consistency was acceptable for the Q-CHAT-24 (Cronbach´s α=0.78). The internal consistencies were analyzed for the Q-CHAT-24 Factors, and they were good for factor 1 "Communication and Social Interaction" (Cronbach´s α=0.85) and acceptable for factor 2 "Restrictive and Repetitive Patterns" (Cronbach´s α=0.74).

3.4 Comparison between Q-CHAT-24 and ADOS-2 module T scores

Seventy-one cases (23.12%) scored 38 points or more on the Q-CHAT-24, qualifying as Autistic Risk. The mean score in the Autism Risk group was 46.9 (range 38–69, SD=8.0) and the mean score in the Non-Autism Risk group was 26.09 (range 6–37, SD=7.23). The differences observed were statistically significant (t(305) =-19.54, p<0.001).

Of the cases identified as Autism risk, 10 caregivers of children at risk for autism did not agree to undergo with the ADOS-2 confirmatory assessment. 48 cases (78.6%) were confirmed as Autism by the ADOS-2 Module T and 13 (21.3%) were excluded as such. As a control measure, 22 non-risk children were assessed with the ADOS-2 Module T, and all of them were excluded as autistic. Figure 2 summarizes the study design and the selection of participants according to their classification as Autism Risk/Non-Risk according to the Q-CHAT-24 and according

TABLE 1 Socio-demographic characteristics of the sample studied (n=307).

	n	%
Gender		
Male	169	54.0
Female	144	46.0
Go to the nursery	121	38.8
Family History		
Epilepsy	37	12.1
Language Disorder	48	15.5
Learning Disorder	41	13
Intellectual Disability	23	7.2
Psychiatric Disorder	38	12.3
Autism Spectrum Disorder	15	5.0
Location of the house		
Urban	245	78.2
Rural	68	21,8
Caregiver's Education Level		
Basic Incomplete	15	4.9
Basic Complete	16	5.2
Secondary Incomplete	37	12.1
Secondary Complete	142	46.4
Superior Technical	44	14.4
Superior University	52	17.0
Employment status		
Employed	178	56.9
Unemployed	135	43.1
Family income		
Less than $USD190	28	9.1
$US 190 - $US 380	113	36.1
$US 380 - $US 630	100	32.0
$US 630 - $US 1,140	49	15.8
$US 1,140 - $US 1,500	11	3.4
Over $US 1,500	12	3.6

to the Autism Confirmed/Excluded status according to the ADOS-2 Module T.

The mean score of the Q-CHAT-24 in the group of cases Autism confirmed was 48.23 (range 38–69, *SD*=8.44) and 37.17 (range 28–44, *SD*=3.19) for the group of Autism excluded. The observed differences were statistically significant (*M-W* =122, p<0.001).

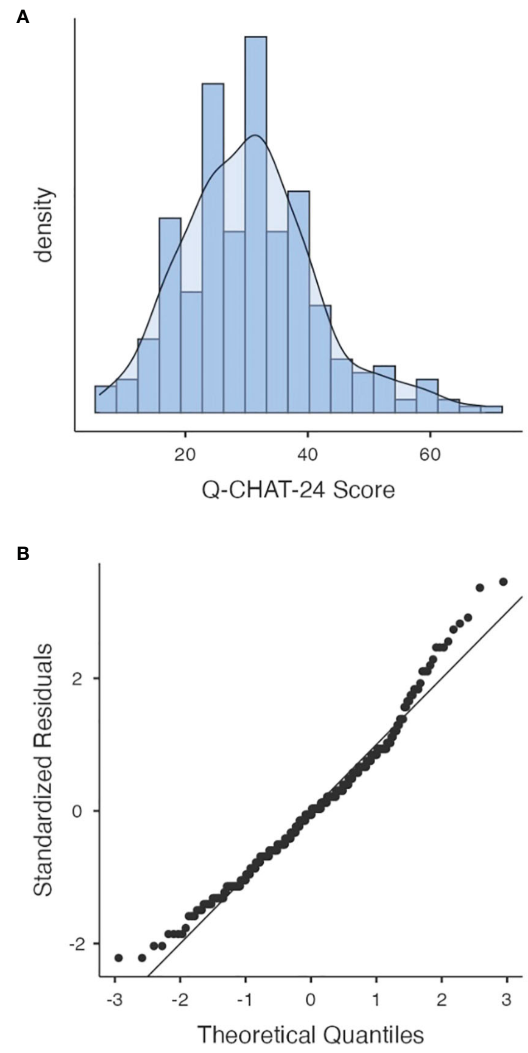

FIGURE 1
Histogram and Q-Q Plot for Q-CHAT-24 scores distribution in the studied sample (n=307). Figure shows distribution **(A)** and standardized normal probability plot **(B)** of the Q–CHAT total score in the screened population (n = 307).

The correlation between scores on the Q-CHAT-24 and scores on the ADOS-2 Module T was positive and statistically significant (r=0.65, p<0.001). This correlation was high, positive and significant for the Confirmed and Excluded Autism groups (r=0.65 and r=0.64, respectively). Figure 3 shows a scatter plot with the trend curve for the correlation between scores on the ADOS-2 Module T and the Q-CHAT-24 in the ASD and non-ASD groups.

3.5 Predictive validity Q-CHAT-24

Receiver operating characteristic (ROC) curve analyses were performed. The AUC values were 0.93 with statistical significance (p<0.01). For the cut-off point of 38, the Sensitivity, Specificity and Youden index values were 0.89, 0.8 and 0.7, respectively. The Positive Predictive Value (PPV) was 86% and the Negative Predictive Value (NPV) was 85%. Figure 4 shows the ROC curve of the described analysis.

TABLE 2 Rational analysis of the items: Item-total Q-CHAT-24 Correlation (n=307).

Items	Item-total correlation
	(Pearson`s *r*)
1. Looks when called by name	0.59‡
2. Eye contact	0.58‡
3. Lines objects up†	0.13
4. Understands child's speech	0.31‡
5. Protoimperative pointing	0.48‡
6. Protodeclarative pointing	0.54‡
7. Interest maintained by spinning object†	0.36‡
8. Number of words†	0.44‡
9. Pretend play	0.49‡
10. Follow a look	0.54‡
11. Sniff/lick unusual objects†	0.43‡
12. Use of hand as tool†	0.21‡
13. Walk on tiptoes†	0.28‡
14. Adapt to change in routine	0.32‡
15. Offer comfort	0.49‡
16. Do same thing over and over again†	0.41‡
17. Typicality of first words	0.48‡
19. Gestures	0.57‡
20. Unusual finger movements†	0.45‡
21. Check reaction	0.22‡
22. Maintenance of interest†	0.33‡
23. Twiddle objects repetitively†	0.45‡
24. Oversensitive to noise†	0.38‡
25. Stare at nothing with no purpose†	0.54‡

†Reverse-scored items.
‡Satisfactory correlation (0.5≥r≥0.2).

4 Discussion

The aim of this study was to examine some psychometric characteristics of the Chilean-adapted version of the Quantitative Checklist for Autism in Toddlers (Q-CHAT-24) (14) in a group of unselected children (community sample). This version was administered remotely through an online version during the pandemic period to caregivers of children, aged 18–24 months, registered in four primary care polyclinics of the Health Service Araucanía Sur, Chile.

Q-CHAT-24 total score showed a normal distribution, replicating previous findings and in other cultural contexts, both in community sample (24, 26–29) and confirms the quantitative and dimensional nature with which Q-CHAT was conceived (26).

We found significantly higher scores for boys than for girls. These results are consistent with epidemiological and genetic evidence showing that males are associated with higher autistic traits in general population samples (38–40).

The high percentage of children scoring above the cut-off point is consistent with previous findings from the use of the Q-CHAT in the Chilean population reported by Roman-Urrestarazu et al. (24). This percentage is probably determined by the fact that the Q-CHAT-24 identifies autism risk in a heterogeneous child population that shares manifestations with other developmental trajectories such as neurodevelopmental delays.

Rational analysis of the Q-CHAT items showed that 23 of the 24 items have item-total correlations with satisfactory values, which is quantitatively higher than that observed in the 25-item version in the Chilean population (24).

Reliability analysis show acceptable values for the overall scale (α=0.78) and for factor 2"Communication and Social Interaction" (α=0.74), and good for factor 1 "Restrictive and Repetitive Patterns" (α=0.85).

Finally, regarding the evidence of predictive validity, the Q-CHAT-24 showed Sensitivity and Specificity values that met the criteria defined *a priori* as necessary to be used for screening: sensitivity and specificity > 0.8, sensitivity ≥ specificity, and Youden index ≥ 0.70. Interestingly, for Q-CHAT-24 the cut-off point that best harmonizes the optimal values of sensitivity and specificity (cut-off point of 38), is higher than the one originally proposed by Allison et al. (2008) (26) and replicated by Stevanovic (2021) (29), for a longer version (25 items). As De Leeuw et al. (2020) suggest (41), it is possible that the higher quantification of symptoms observed in our study in relation to other reports is due to the cultural differences that can be observed between cultures in the quantification of autism symptoms. For example, Magaña and Smith (2013) (42) reported lower parental concern in parents of Latino children compared to parents of White American children.

Considering the polytomous nature of the Q-CHAT-24 items, sensitivity and specificity values probably do not account for the full complexity of the test and should be complemented with Predictive Value metrics. In our study, the observed PPV value is high (86%) but lower than those observed by Roman-Urrestarazu et al. (2021) (25)in another sample of Chilean population.

4.1 Limitations

The low response rate (36.6%) is an important limitation of this study and is likely related to self-selection bias and the high rate of scores above the cut-off point for autism risk (23.12%) observed in our sample. This may limit the generalizability of these results to a general population sample.

The study design did not consider the application of the diagnostic Gold Standard (ADOS-2 Module T) (43) to an equal

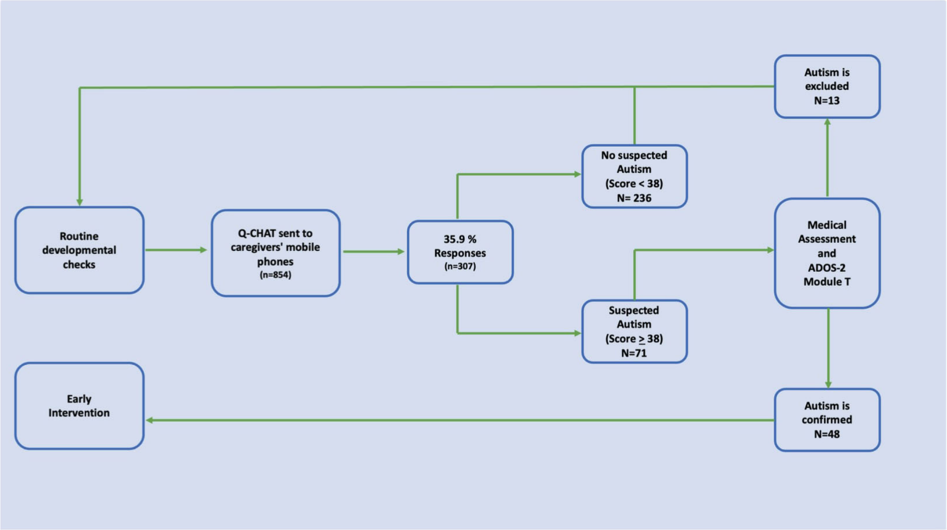

FIGURE 2
Study design overview and selection of participants (n=307). Eight hundred and fifty-four caregivers were invited to participate. Of these, 307 agreed to participate by signing the informed consent form and completed the socio-demographic questionnaire and the Q-CHAT-24. Seventy-one children (23.1%) were identified as being at risk for autism. Of these, 48 were confirmed by the ADOS-2 module T as Autism.

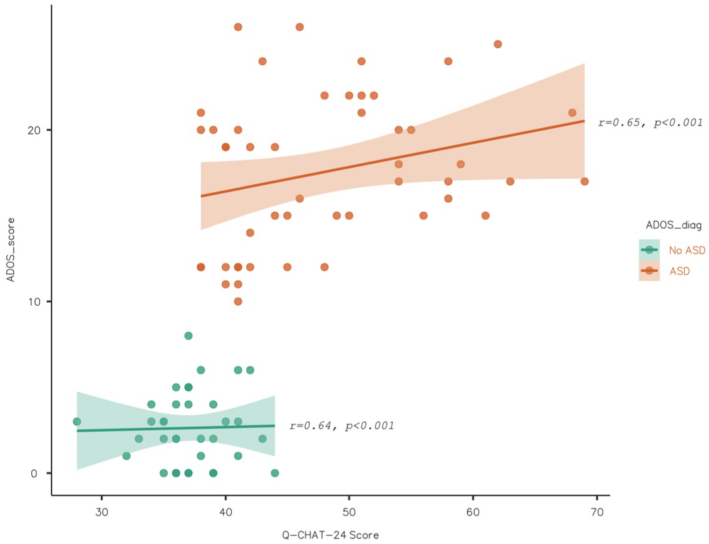

FIGURE 3
ADOS-2 and Q-CHAT-24 Scatterplot (n=307). Figure shows a Scatterplot with a tendency curve to graph the correlation between ADOS-2 Module T and Q-CHAT-24 scores in both ASD and No-ASD groups. The correlation between these scores was high, positive, and statistically significant in both groups (r=0.65, p<0.001 and r=0.65, p<0.00, respectively).

number of control cases without risk of autism, so the specificity values of the test should be taken with caution.

4.2 Conclusions

In accordance with the objectives of this study, evidence of reliability and predictive validity was demonstrated for the Q-CHAT-24 in this Chilean population. More importantly, this study provides Sensitivity and Specificity data for a remote application version of an autism screening tool already validated in Chile. The implications of this have to do with the possibility of establishing a remote assessment system for children at risk of autism on a population scale.

Future directions following this study include examining the Q-CHAT-24 as a measure of early detection of autism in larger samples and conducting other follow-up studies and thus confirming the evidence of predictive validity. Similarly, it would

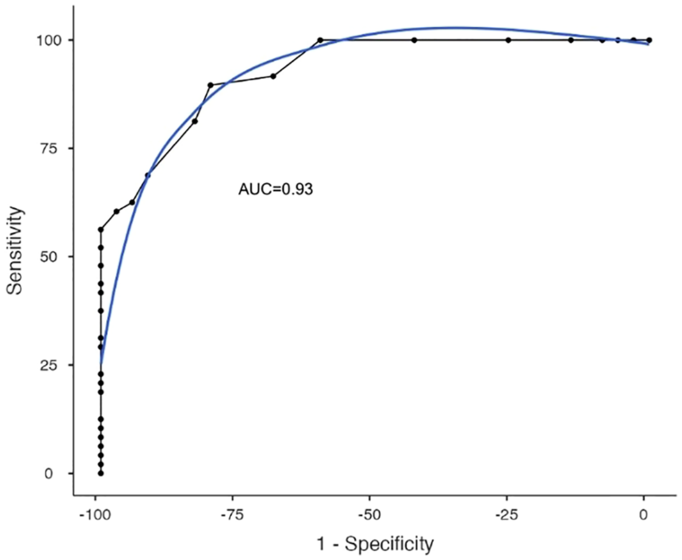

FIGURE 4
Q-CHAT-24 ROC Curve. The figure shows the receiver operating characteristic (ROC) curve analysis of Q-CHAT-24 in the studied sample. The AUC values were 0.93 with statistical significance (p<0.01).

be useful to incorporate other developmental variables such as measures of language and social development in future studies.

Finally, prospective studies could provide evidence on the eventual impact that isolation and lack of socialization may have had on Autism diagnosis rates during the period of the COVID 19 pandemic.

Data availability statement

The datasets presented in this article are not readily available because the data sets generated and analyzed during this study are not publicly available because of our agreement with the parents of the children. Requests to access the datasets should be directed to gabriel.gatica@uc.cl.

Ethics statement

The studies involving humans were approved by Ethics Committee of Araucanía Health Service, Chile. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

GG-B: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. AM-F: Writing – review & editing, Writing – original draft, Validation, Supervision, Formal analysis, Data curation. FS-S: Writing – review & editing, Writing – original draft, Resources, Investigation. CP-D: Writing – review & editing, Writing – original draft, Resources, Investigation. RK: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation. KC: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Formal analysis, Conceptualization. AR-U: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Formal analysis, Conceptualization.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Cecilia Montiel Nava,
The University of Texas Rio Grande Valley,
United States

REVIEWED BY
Flavia Lecciso,
University of Salento, Italy
Paulina Buffle,
University of Geneva, Switzerland
Elisabetta Filomena Buonaguro,
University of Naples Federico II, Italy
Makoto Wada,
National Rehabilitation Center for Persons
with Disabilities, Japan

*CORRESPONDENCE
Miguel Castelo-Branco
✉ mcbranco@fmed.uc.pt

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Brief report: caregivers' well-being in families with neurodevelopmental disorders members during COVID-19: implications for family therapy

Daniela Sousa[1,2,3], Ana Ferreira[1,2], Joana Sequeira[3], Marilyn J. Monteiro[4], Marco Simões[1,5] and Miguel Castelo-Branco[1,2]*

[1]Coimbra Institute for Biomedical Imaging and Translational Research (CIBIT), Institute for Nuclear Sciences Applied to Health (ICNAS), University of Coimbra, Coimbra, Portugal, [2]Faculty of Medicine, University of Coimbra, Coimbra, Portugal, [3]Instituto Superior Miguel Torga (ISMT), Coimbra, Portugal, [4]PhD Licensed Psychologist, St. Petersburg, FL, United States, [5]Centre for Informatics and Systems (CISUC), University of Coimbra, Coimbra, Portugal

Neurodevelopmental disorders affect the lifespan of diagnosed individuals and their families. COVID-19 challenged these families with daily routine unpredictability requiring rapid adaptations. Moreover, associations and schools were closed, leaving these families without regular social support. Here, we investigate which individual and family factors can predict the caregiver's depressive state and overall burden. An online study took place between 2021 and 2022. A total of 32 caregivers (30 women; 48 ± 8.22 years old; range 26 to 63 years old) reported having a family member with a neurodevelopmental disorder, the majority diagnosed with autism spectrum disorder. Caregivers responded to a protocol to assess the burden, resilience, depressive, anxious, and stress symptomatology, as well as the behavior of the diagnosed individual. Hierarchical multiple regressions were performed to identify protective and risk factors for the caregivers' well-being. Caregivers' depressive state was explained by 29.3% of the variance of the family cohesion factor, indicating that high levels of balanced family cohesion represent a crucial protective factor for reducing the caregiver's depressive state. Additionally, overall caregiver burden was explained by 17.8% of the variance due to self-perception and 26.4% due to family cohesion, with the caregiver's self-perception playing an important protective role in the overall perception of burden. The proportion of male and female respondents seems to corroborate the significant role of women in caregiving. These results emphasize the importance of considering both individual and family factors of caregivers during interventions, which have implications for family therapy with families of members diagnosed with neurodevelopmental disorders, specifically with autism.

KEYWORDS

COVID-19, autism, neurodevelopmental disorders, caregiver's well-being, family therapy

1 Introduction

Neurodevelopmental disorders (NDDs) are manifested typically early in life during the development. The American Psychiatric Association in the Diagnostic and Statistical Manual of Mental Disorders (5th edition, DSM-5) proposed a broadening of categories to cover NDDs, including the intellectual, communication, autism spectrum, attention-deficit/hyperactivity, specific learning, motor, tic, and other NDDs without specifications. These disorders are characterized by impairments in personal, social, academic, or occupational functioning (1). In addition, they are lifelong disorders and require an informal care provision by family members that are many times invisible to others. Therefore, parents navigate between health services, multiple therapies, educational responsibilities, and emotional and behavioral problems single-handedly (2).

Studies showed that having a family member with an NDD was associated with negative outcomes for caregivers, which include burnout, emotional exhaustion, depression, and physical fatigue (3). Usually, these parents experience high levels of stress compared with other chronic diseases (2, 4, 5). Additionally, it is known that stress is associated with parenting self-efficacy perception and influences the intervention outcomes of the individual with a NDD diagnosis (6). However, different family members, such as siblings, can assume caregiver roles. Sibling-focused parentification, where siblings support a brother/sister with an NDD emotionally or instrumentally, can lead to both positive (e.g., responsibility, high self-efficacy, empathy) and negative outcomes (e.g., rejection, guilt, anxiety, and depression) (7–9). The father's role appears to be less involved (10), with a lower propensity for depressive symptoms (7) and a higher perception of competency (11). Their distress may manifest differently and warrants further exploration (12). In most studies, the focus on caregivers shows that women are more represented (5, 7–9). The COVID-19 quarantine challenged these families with an array of problems, potentially further increasing caregivers' stress levels (2, 13). People with NDD find stability in routines by knowing what is expected at each moment (5). The unpredictability due to the COVID-19 context led to anxiety, frustration, and emotional breakdowns (2, 14, 15). Caregivers had to deal with an increased incidence of these states and the unexpected changes associated with the closure of schools and other support services, which before allowed them to have some respite care from informal care provision. Furthermore, the circumstances of COVID-19 potentially induced an environment where the boundaries between the caregiver's roles (e.g., professional, parental) were diluted, which may contribute to an increase in feelings of burden.

Home quarantine and isolation challenged families dealing with worsening symptoms (5, 16), behavioral and emotional regulation, and routine adherence difficulties (2) with interruptions of support services (5). The exposure to COVID-19 may have contributed to intensified stress responses leading to aggression and irritability (2), and, in autism, with a higher probability of using maladaptive coping behaviors, which exacerbates the characteristic autistic behaviors (6, 17). A low level of support and sharing in coparenting is a risk factor for parental distress (18). Adults with NDD have reported higher rates of anxiety symptoms but may nevertheless show improvements in depression levels (due to less exposure to negative feedback; relief of day-to-day demands) (19). NDDs may unveil maladaptive feedback loops that can occur during challenging times within a familiar context of informal care provision. Moreover, a study found a relationship between the worsening of the symptomatic changes in children and higher parental distress levels, which may lead to an escalating positive feedback loop (5), and this finding seems to be independent from the type of NDD diagnosis (18). Therefore, the families of people with NDDs are at greater risk of being negatively impacted by the pandemic, as an external source of family stress (15) describing, e.g., feelings of loneliness (18). However, the more time with the family and strengthening relationships may on the other hand have helped to get to know better their child and the experience of closeness were positive aspects reported (18).

Families faced the early challenging time of COVID-19 with preoccupations about future lockdowns, stability of living situation, and scarce financial resources for day-to-day expenses (5). People with NDDs struggled to comply with COVID-19 recommendations (e.g., social distancing; use of masks) (5). Studies found that the interruption of routines and the high stress related to the lockdowns and restrictions were associated with a higher impact on child and parent well-being (5). Another study showed that during COVID-19 when the mother was suffering from a depressive state, a negative interaction with routines and children's maladaptive behaviors were identified (14). This type of interaction was seen previously in other natural disasters and even worse during emergencies (14).

It is acknowledged that individual characteristics, such as child behavior problems, maternal stress, coping style, and familiar functioning dimensions, namely, family cohesion, have been consistently related with depressive symptoms on caregivers (20). Therefore, the caregiver's depressive state and the overall relational burden should be understood in the context of the informal care provision relationship, which is markedly demanding in a highly stressful context, such as the COVID-19 pandemic. Therefore, based on previous evidence, we expected to identify whether individual factors, such as self-perception, and family factors, such as family cohesion, could have either a protective or risky impact on the development of caregivers' depressive states and perception of overall burden. Additionally, we anticipated identifying a gender tendency associated with the caregiving role, with a greater representation of women.

2 Methods

2.1 Procedure

The study was approved by the Faculty of Medicine ethics committee from the University of Coimbra (Portugal). Written informed consent was obtained from the respondents. The online study took place from April 2021 until March 2022 on the Neurohab platform (21). The sociodemographic questionnaire was developed to explore the COVID-19 pandemic impact on individual and family daily life (Sociodemographic questionnaire in Supplementary Materials). Additionally, the protocol included a variety of self-report instruments to evaluate the caregiver's psychopathology, resilience dimensions, burden, and maladaptive behavior of the individual with a NDD. The overall online study took approximately 45 min to fill out.

2.2 Participants

There were 32 respondents (30 women and 2 men; mean (*M*) age = 48 years old, standard deviation (*SD*) = 8.22) reported having a family member with a prior formal NDD diagnosis, according to the DSM-5 classification. However, only 27 caregivers completed the entire protocol. This sample originates from 702 adults who responded to a larger online protocol about COVID-19 pandemic. The degree of relatedness of caregivers to the member diagnosed with an NDD, as well as the percentages of NDD categories, is presented in Table 1. Down syndrome was reported and included, as it is considered a neurodevelopmental disorder due to the presence of neurodevelopmental abnormalities (22). It is the most frequent cause of intellectual disability and has a high co-occurrence with autism spectrum disorder (23–25). Autism spectrum disorder was the diagnosis most frequently reported in our sample. The age of the family member with the NDD was on average 22.78 years old (*SD* = 19.80; range 4 to 86 years old). Sample characterization details can be found in Supplementary materials.

2.3 Materials

Sociodemographic questionnaire and protocol measures are presented and additional information can be found in Supplementary Material, Table S3.

2.3.1 Depression Anxiety Stress Scales 21 items

Depression Anxiety Stress Scales (26, 27) (DASS-21) were developed to measure anxiety, depression, and stress. Depression was defined as a result of motivation and self-esteem loss, anxiety as a long-lasting state of anxiety and intense responses to fear, and stress as excitation states and persistent tension (e.g., difficulty relaxing, irritability, and agitation) combined with frustration and disappointment. These scales assumed that mental disorders are dimensional, and the overall scale is composed by 21 items about negative emotional symptoms. The caregivers' rated the affirmations by evaluating on a four-point Likert scale of severity/frequency related to if they have experienced that symptom during the past week. These scales provide a score per scale and a total score, with higher scores reflecting higher levels of negative affective state.

2.3.2 Resilience Scale for Adults

The Resilience Scale for Adults (28–30) (RSA) assessed resilience as a multidimensional concept theoretically based on the assumptions of protective resources in three areas: individual psychological abilities; family context and support; and external support systems that provide an efficient coping and adjustment (11). Therefore, RSA is composed of 33 items distributed across different dimensions, namely, self-perception defined as the self confidence about abilities, judgments, personal agency, and real expectations; future planning which is the ability to plan, with an optimistic vision, and is oriented by clear and realistic goals; social competencies related to the flexibility within social relationships, as friendships, being at ease in social contexts and the positive use of humor; structured style which is about the ability to have a routine, good time management, and preference for goals and plans; family cohesion which is associated with shared values, appreciation in sharing time, loyalty, optimistic vision of the future, and a feeling of mutual appreciation and support; social resources which are related to social support when individuals have a trusted person outside the family to whom they can ask for assistance. Caregivers must choose within 1 to 7 the response that suits them. This measure has a score per dimension and a total score, with higher results indicating better resilience.

2.3.3 Revised Burden Measure

Revised Burden Measure (31, 32) (RBM) is used to evaluate the caregiving burden and gratifications related to the informal care provided to individuals with chronic health problems. This scale is based on a relational and social context and includes the evaluation of positive affect related to the care provision, which can coexist with negative affect. The questionnaire has 22 items divided in four subscales: the relationship burden which is defined as the caregiver's perception of demands required by the person, which are not aligned with the medical condition; the objective burden as a

TABLE 1 Degree of relatedness between the caregiver and the member with a neurodevelopmental disorder and the neurodevelopmental disorders diagnoses.

Degree of relatedness	Father or mother	Sister or brother	Son	Stepmother	Other (missing response)	
n **(Percentage %)**	23 (71.9%)	1 (3.1%)	6 (18.8%)	1 (3.1%)	1 (3.1%)	
Diagnoses (DSM-5)	**Autism spectrum**	**Hyperactivity and/or attention deficit**	**Ticks disorder**	**Down syndrome**	**Intellectual disability**	**Motor disorder**
n **(Percentage %)**	19 (59.4%)	2 (6.3%)	1 (3.1%)	6 (18.8%)	2 (6.3%)	2 (6.3%)

negative state which results from the care provided during the caregiver's free time; the subjective burden as the global negative affect associated with the care provision; and the gratification defined as the positive psychological state associated with informal care. Caregivers are invited to reflect on how their lives changed as a result of care provision on a 5-Likert scale. This measure gives a score per subscale and a burden overall score. The higher scores in the burden and/or uplifts scales indicate a significant modification in that caregivers' life dimensions.

2.3.4 Aberrant Behavior Checklist-Community

The Aberrant Behavior Checklist – Community (33, 34) (ABC-C) evaluates the presence and variety of maladaptive behaviors across five subscales: Irritability, Agitation, Crying; Lethargy, Social Withdrawal; Stereotypic Behavior; Hyperactivity, Noncompliance; and Inappropriate Speech. The 58 items are rated on a 4-point Likert scale, with higher scores indicating more severe problems (34). The rater is asked to consider behaviors that have interfered with the individual development, functioning, and/or social as problematic during the last 4 weeks (35). The scores are obtained per subscale (36).

2.4 Data analysis

All statistical analyses were performed in IBM Statistical Package for the Social Sciences (SPSS), Version 25. Descriptive analyses were performed to explore the prevalence of caregivers' symptomatology, burden, and resilience dimensions and behavior dimensions of the individual with an NDD. The normality assumption for the instrument's dimensions selected was verified using the Shapiro–Wilk test. The variables depression (DASS-21), the burden (RBM), and the irritability (ABC) were not normally distributed (p <.05). Two exploratory analysis using hierarchical multiple regressions were performed to identify protective and risk factors for the caregivers' well-being (Supplementary Material, Exploratory Analysis). Hence, two final multiple regressions were performed, building upon prior exploratory analysis investigating statistical significance of addition of predictors identified in the previously explored models (Supplementary Material, Hierarchical Multiple Regression Assumptions). Additionally, a binomial test was done to compare if there is a difference in proportions between groups regarding caregivers' gender.

3 Results

3.1 Individual and family factors characterization

The results obtained with the DASS-21 revealed that 12 (37.6%) caregivers reported a depressive state ranging from mild to extremely severe. Concerning anxiety, 10 (31.4%) caregivers reported levels between mild to extremely severe, and in the stress scale, 13 (40.6%) caregivers reported mild to severe levels of stress. Figure 1 details the symptomatology severity across DASS-21 scales.

The RBM results showed that 17 (53.1%) caregivers felt an average to high level of relationship burden and 18 (56.3%) an average to high level of objective burden. In the subjective burden, many caregivers felt an average to high level of burden (n = 22, 68.7%), and most of them felt an average to high gratification associated with the informal care provision (n = 26, 81.3%). Figure 2 synthetizes the results obtain in the RBM.

Caregiver's resilience dimensions and behavioral characterization of the individual with NDD can be found in Supplementary Material (Supplementary Figures S1, S2).

3.2 Caregiver's depressive state and overall burden prediction

The first model included the family cohesion as a predictor of caregiver's depressive state, F (1, 25) = 10.351, p <.05. We found that the family cohesion led to a R^2 of .293. Therefore, 29.3% of the variance explained in the depression scores can be attributed to the family cohesion. This result indicates that family cohesion was significantly negatively associated with the caregiver's depressive sate (B = −3.413, t = −3.217, p = .004). Therefore, the change in one unit for family cohesion score will result in −3.413 (95% confidence interval CI, −5.598 to −1.228) in the value of depression scores. The addition to the model of subjective burden led to a statistically significant model, F (2, 24) = 6.503, p <.05. However, the addition of this predictor did not prove to be significant.

Regarding the caregiver's overall burden prediction, we introduce in the first model the self-perception, F (1, 25) = 5.429, p <.05. This individual factor explains 17.8% of the overall burden. The family cohesion addition to the second model led to a statistically significant increase in R^2 of .264, F (1, 24) = 11.366, p <.05, and maintaining this second model statistically significant, F (2, 24) = 9.523, p <.001. These results show that caregiver's overall burden prediction is intimately and negatively associated with self-perception (B = −6.233, t = −2.330, p = .028) and family cohesion (B = −11.547, t = −3.731, p = .003). Hence, the change in one unit for self-perception and family cohesion will result in −6.233 (95% CI, −11.742 to −.724) and −11.547 (95% CI, −18.615 to −4.478) in the value of overall burden, respectively. Table 2 summarizes these results.

3.3 Caregiver roles by gender

In this sample, we have a statistically significant difference in caregivers' gender with a .94 proportion of women to a .06 proportion of men (p <.001).

4 Discussion

The protective factors that can be resources against the development of psychiatric disorders (e.g., depression) have been seen as a significant force behind healthy adjustment to life stressors (e.g., financial issues, maladaptive behaviors) or to regain and

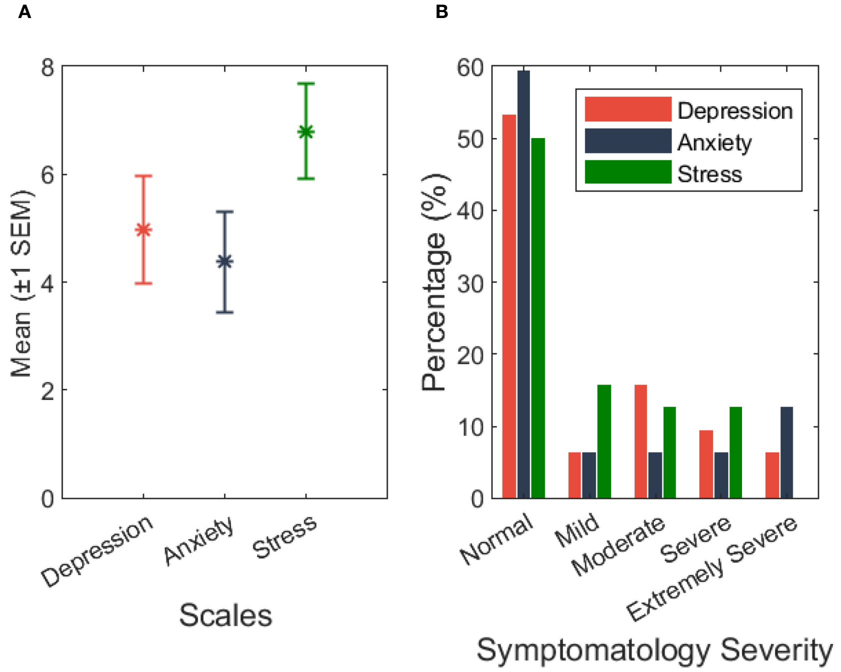

FIGURE 1
(A) DASS-21 mean (*M*) ± 1 standard error of mean (*SEM*) by classification (please see Table S3, Supplementary Material). **(B)** DASS-21 characterization of symptomatology severity (*N* = 29) in percentage (%).

maintain mental health (11). It is known that families of children with NDDs, namely, the parents, have a high risk of presenting high levels of depression and anxiety, due to several stressors (e.g., diagnosis severity, relation with the child) (37). In this study, we investigated how individual and family factors can predict the levels of depression and the overall burden of caregivers to better understand which factors should be addressed to prevent and intervene with these families.

Our sample is aligned with the literature where women, specifically mothers, are usually the primary caregiver when special care is required in chronic diseases (16, 20, 32, 37). Previously to COVID-19, a meta-analysis identified that the

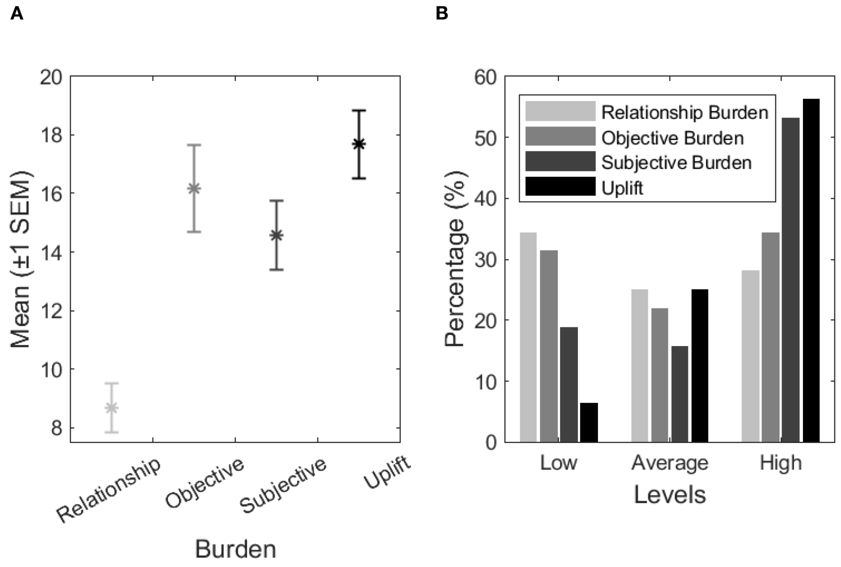

FIGURE 2
(A) RBM *M* ± *SEM* categorization classification (please see Table S3, Supplementary Material). **(B)** RBM results characterization on levels of burden and uplift or gratification by percentage (%) (*N* = 28).

TABLE 2 Hierarchical Multiple Regression results for caregiver's depressive state on the left side of the table and Hierarchical Multiple Regression results for caregiver's overall burden on the right side.

	Depressive state				Overall burden				
	Model 1		Model 2			Model 1		Model 2	
Variable	*B*	β	*B*	β	Variable	*B*	β	*B*	β
Constant	23.531		12.748		**Constant**	68.200		108.470	
FC	−3.413	−.541	−2.148	−.341	**SP**	−6.233	−.422	−1.482	−.100
SB			.272	.314	**FC**			−11.547	−.606
R^2	.293*		.351		R^2	.178*		.442*	
F	10.351		6.503		***F***	5.429		9.523	
ΔR^2	.293		.059		ΔR^2	.178		.264*	
ΔF	10.351		2.170		ΔF	5.429		11.366	

$N = 27$, *$p < .05$, **$p < .001$.
FC, Family Cohesion; SB, Subjective Burden; SP, Self Perception.

relationship mother–child was a risk factor, and it was associated with higher rates of depression in mothers compared with fathers (37). Also, high ratings of depression were associated with low family support/cohesion, low maternal health, high levels of stress, less effective coping styles, and the presence of more than one child with NDD (20). These results highlight the importance of understanding the challenges of these families in "typical" periods versus "atypical" periods for family life, such as the COVID-19 pandemic.

Empirical evidence showed that there is a bidirectional and reciprocal effect between the challenges of caring a children or adult with NDD and the quality of the relationship, which reinforces the importance of family involvement (7–9, 16, 18). For example, in a systematic review and meta-analysis, the authors found that parents of children with autism had moderate effect sizes for elevated depression (37). In our study, we found that balanced family cohesion (which means a family cohesion that allows the individual and family development, reflecting the emotional bonding that family members have toward one another) to the prediction model of the caregiver's depressive state increased the variance explained by this protective factor by 29.3%. This result emphasizes the importance of working with families in which there are family members with NDD. This finding was supported by the result obtained with the addition of family cohesion to the prediction model of the caregiver's overall relational burden explaining 26.4% of the variance. Furthermore, balanced family cohesion can be a protective factor for the caregiver's mental health and in the feeling of subjective burden resulting from the informal care provision. The family cohesion as a protective factor, which can alleviate the negative impact of life stress events, was previously reported (38). Hence, the alteration of burden perception may be a potential factor to improve caregiver's adaptation to outcomes (31). The combination of individual and social factors, namely, resilience, which includes the family support or social competence, seems to be crucial to withstand life stress (11). Studies have shown that resilient individuals seem to cope more functionally and flexibly with stress, and these attributes are developed early in life, for example through secure attachment, and resilient women seem to elicit and provide more social support (11). Furthermore, family resilience includes family cohesion, which is a fundamental process associated with well-being during serious crises (38, 39). In addition, a literature review showed that during COVID-19, it was important to maintain a good and healthy communication and to find positive activities to do, between family members, to create a sense of togetherness, trust, cohesion, and happiness (39). Moreover, results in family cohesion during COVID-19 in families without family members with NDD showed evidence of increasing family cohesion strongly associated with health status, namely, families with highly balanced family cohesion promoting healthy behaviors (40). Contrarily, our results indicate that when there is an increase in the caregivers' overall burden and depressive state, there is an association with low balanced family cohesion. Therefore, we hypothesized that during the COVID-19 pandemic, there was a rigidification of roles in those families, amplifying the perception of disconnection and burden without social and family support. Then, providing family support is specifically important since balanced family cohesion is perceived as a high sense of connectedness, affection, and support that allows positive individual growth with autonomy and effective development of family functions (40).

Lastly, it is important to underline those parents of individuals with autism brain style which are known to show more distress when compared with other NDDs (5). Additionally, the few studies that have explored the effect of COVID-19 pandemic on the well-being of parents of children with NDD highlighted the need to support these parents (5, 13, 18). Therefore, the creation of support services for caregivers' mental health is crucial to avoid decreasing the quality of life and well-being (14). It is universally recognized that families are the constant in the individual's life and are best suited to determine their family member's needs. However, in challenging times, the coping skills of these families could suffer from the interaction effects of individual characteristics and family functioning. Therefore, it is of utmost importance to understand the individual and family factors that could be addressed during interventions with these families. Family therapy approaches are appropriate to respond to individual and family needs by creating a secure context for all family members to share their perspectives about problems. Narrative family therapy can be useful by creating narrative transformations that shape individual and family discourses. This approach proved to be effective in a wide range of mental health conditions (41). According to Monteiro (2021), this approach to support families in which a member has NDD, namely, autism brain style differences, has been less explored or developed. However, it may be appropriate for a range of NDDs considering the family life cycle stage. This approach allows the therapist to create the context to develop therapeutic conversations with the family about the strengths and differences of the individual with NDD based on descriptive strength language (42). Concurrently, in this process of shifting the narratives, the therapist will work on the caregiver's self-perception. This resilience dimension includes self-confidence about abilities, judgments, personal agency, and realistic expectations. However, caregivers oftentimes have doubts about their capacities to respond adequately to the needs of their family member. Hence, caregivers can develop a negative self-perception which impact their sense of competency to deal with daily life challenges and this negative sense can be increased by external sources of stress. This process can create a powerlessness narrative which needs to be transformed into a narrative of competence during the therapeutic process. Therefore, the therapeutic conversations will focus on creating a plot of new emerging narratives about the past and present singularities, which will allow to create a sense of hope and competency for the future in the relational context. Additionally, it is in this process that a shift can occur in burden perception. Accordingly, by the therapist exploration of singularities, which refers to unique moments or exceptions that are in line with the family's identity, we will promote novelty in individuals' and families' responses that will be amplified during the therapy (43). For these therapeutic conversations, it is important for the therapist to be aware of the narrative change dimensions which should be questioned and perturbed to open space for the emergence of these new stories (43). The construction of new storylines about the individual and the family, concerning the difficulties, feelings of appreciation, and support within the family context, can emerge. Additionally, an optimistic vision of the future can be co-constructed by having therapeutic conversations about the strengths of the individual with NDD and how the challenges can be overtaken by them, together. During this process, family and individual values are shared and amplified in session creating a sense of loyalty between family members, since all are aligned in a core dimension of family functioning, which means that family cohesion works along with therapy.

4.1 Limitations

This study has some limitations; that is, it is a cross-sectional study with a relatively low sample size, although one must consider that the base sampling is from a larger study. Additionally, there is a heterogeneous number of families regarding the NDD diagnosis according to DSM-5 classification. Moreover, we only have the response from the point of view of one caregiver, in particular given the larger adherence of women, and we used self-report measures, which reflect the subjective perception of the respondent. Moreover, we acknowledge the possibility of misunderstandings during the protocol completion. Therefore, these results should be interpreted with caution. Longitudinal online studies should be conducted to reach various family members, aiming to better understand the caregiving systems in NDDs in different times during normative crises (e.g., transition from adolescence to young adult) or unexpected (e.g., pandemic). Future research should include efficacy studies to provide evidence of the effectiveness of narrative family therapy in NDDs and to deepen our understanding of the long-term outcomes on family cohesion and the mental health of family members.

4.2 Future directions

Finally, our results point out at the individual level the importance of the caregiver's self-perception, such as self-confidence to face daily life challenges, which can impact on burden perception. Additionally, on the family level, the sense of togetherness seems to be crucial for these families. These results support the importance of the relational context during an experience of high external stress, such as the COVID-19 pandemic. Future works and clinical practice should pay particular attention to the individual and family factors of caregivers of individuals with NDD, which can impact positively or negatively on their mental health.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Comissão de Ética da Faculdade de Medicina, Universidade de Coimbra. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

DS: Writing – original draft, Visualization, Writing – review & editing, Investigation, Conceptualization. AF: Validation, Writing – review & editing, Investigation. JS: Supervision, Writing – review & editing, Validation, Investigation. MM: Writing – review & editing, Validation, Supervision, Investigation. MS: Software, Writing – review & editing, Validation, Investigation. MC-B: Supervision, Project administration, Funding acquisition, Conceptualization, Writing – review & editing, Validation, Investigation.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2024.1409294/full#supplementary-material

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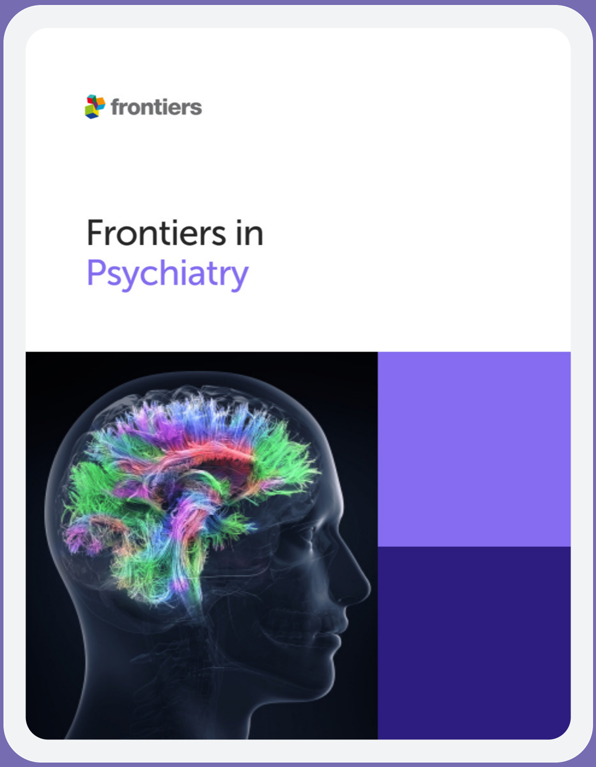

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