

Original Article

Mental health profiles of autistic children and youth during the COVID-19 pandemic

Marina Charalampopoulou BSc^{1,*}, Eun Jung Choi PhD^{1,*}, Daphne J. Korczak MD^{2,3, ID}, Katherine T. Cost PhD², Jennifer Crosbie PhD^{2,3}, Catherine S. Birken MD MSc FRCPC^{4,5, ID}, Alice Charach MD^{2,3,5,6}, Suneeta Monga MD^{2,3}, Elizabeth Kelley PhD^{7,8}, Rob Nicolson MD⁹, Stelios Georgiades PhD¹⁰, Muhammad Ayub MD⁸, Russell J. Schachar MD^{2,3}, Alana Iaboni PhD¹, Evdokia Anagnostou MD^{1,4}

¹Holland Bloorview Research Institute, Toronto, Ontario, Canada

²Department of Psychiatry, Hospital for Sick Children, Toronto, Ontario, Canada

³Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada

⁴Department of Pediatrics, Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada

⁵Child Health Evaluative Sciences, Research Institute Hospital for Sick Children, Canada

⁶Institute for Health Policy, Management and Evaluation, Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada

⁷Department of Psychology, Queen's University, Kingston, Ontario, Canada

⁸Department of Psychiatry, Queen's University, Kingston, Ontario, Canada

⁹Department of Psychiatry, Western University, London, Ontario, Canada

¹⁰Department of Psychiatry and Behavioural Neurosciences, McMaster University, Hamilton, Ontario, Canada

*Shared first authorship: MC and EJC had equal contribution to the first authorship.

Correspondence: Eun Jung Choi, Autism Research Centre, Holland Bloorview Kids Rehabilitation Hospital, 150 Kilgour Rd, East York, Ontario M4G 1R8, Canada. Telephone 416-425-6220, e-mail: echoi@hollandbloorview.ca

ABSTRACT

Objectives: Canadian province-wide lockdowns have challenged children's mental health (MH) during the COVID-19 pandemic, with autistic children being at particular risk. The purpose of our study was to identify sub-groups of autistic children with distinct mental health change profiles, to understand the child-, parent-, and system-specific factors associated with such profiles in order to ultimately inform future interventions.

Methods: Data were drawn from a large Canadian cohort (N=1,570) across Ontario, resulting in 265 autistic children (mean age=10.9 years, 76% male). K-means clustering analyses were employed to partition distinct MH profiles in six MH measures (mood, anxiety, OCD symptoms, irritability, inattention, hyperactivity) and group differences were examined with reference to the above factors. Additionally, we investigated the characteristics of children who accessed acute MH services.

Results: The optimal number of clusters was two; one included those experiencing MH deterioration across all six MH measures (61.3%, 95% confidence interval [CI]=54.9 to 67.4), and a second included youth that did not experience MH changes (38.7%, 95%CI=32.6 to 45.1). Child-specific factors associated with MH deterioration included higher pre-existing internalizing symptoms, high levels of COVID stress. Parental MH challenges and system-specific factors, such as the loss of learning supports, access to physicians and material deprivation, were also associated with MH deterioration. Access to acute MH services were primarily associated with financial insecurity and loss of services.

Conclusions: More than half of autistic children experienced MH deterioration, and person-specific (pre-existing MH, COVID related stress), parent-specific (Parent MH) and system-level (loss of services and material deprivation) characteristics were associated with such decline, providing clinical and policy opportunities for intervention at multiple levels.

Keywords: Autism; Children; COVID; Mental health; Pandemic.

Province-wide lockdowns and school closures have impacted the mental health (MH) of children during the COVID-19 pandemic. Several studies have reported increases in stress,

and internalizing and externalizing behaviours in children and youth (1–4). Children with pre-existing mental health conditions/neurodevelopmental disorders have been particularly

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vulnerable. Although a small portion of children have shown improvements in some MH domains (4–6), most children have experienced a deterioration in their MH (7), with autistic children being one of the most at-risk groups (4,8,9).

Disruptions in various educational and health care services (e.g., academic supports, psychology/social work services, and allied health and medical services) were primary stressors for children and their families during the pandemic (10,11). According to parental reports, the loss of educational and health care services may be particularly detrimental to both autistic children and their families, due to difficulties with changes in routines, but also overall increased need for continuous access to such services (11–14). Parents who have children with neurodevelopmental conditions already experience greater stress and MH challenges than do others, which is recognized to put their children at higher risk for MH difficulties (15–17).

Increases in the use of acute MH services, such as urgent walk-in and emergency department services, may signal MH deterioration (18). A study conducted in Australia just prior to the pandemic reported that children with neurodevelopmental disorders, including ASD, represent one-quarter of all MH presentations to emergency departments, most commonly due to acute behavioural disturbance (19).

The purpose of our study was to identify sub-groups of autistic children who are most at risk of poor MH outcomes during the COVID-19 pandemic, and to characterize subgroup membership using child, parent, and system factors to inform clinical and policy decision making. A secondary goal was to describe the utilization of acute MH services among autistic children.

METHODS

Participants

Data were drawn from a large Canadian collaboration involving two clinically referred and one community cohort across Ontario (N=1,570), previously described (4,20,21). The present analyses employed data from the parents of 265 autistic children (82.8% from POND, 76% male, $M_{age}=10.9$ years). The data were collected in May through December 2020 (Table 1). Autism diagnosis was determined in the original cohorts: diagnosis was supported by ADOS and ADI-R in the POND network, community diagnoses were accepted in the Spit for Science and SickKids Psychiatry cohorts. This study was approved at all institutional research ethics boards and all participants provided informed consent.

Measures

Online surveys were completed by parents May through December 2020. Parent reports were used to collect information as below.

Child mental health status changes

Parents reported their children's MH status changes during lockdown in six measures in two domains: depression, anxiety, and obsessive compulsive disorder symptoms, i.e., internalizing symptoms, and irritability, inattention, and hyperactivity, i.e., externalizing symptoms (e.g., "Compared to the time before the COVID-19 crisis, how is your child's overall mood been?"), using a 5-point Likert scale (1=a lot worse; 5=a lot better) (4).

Table 1. Participant demographics (N=265)

Demographic variables		N (%)
Age (Mean/SD)	10.89 (3.9) years	
Full scale IQ (Mean/SD/Range)	89.08 (23.49) (40–142)	
Child's sex	Female	64 (24.2%)
	Male	200 (75.5%)
	Chose not to answer	1 (0.1%)
Household income (CAD \$)	49,999 and below	57 (21.6%)
	50,000–79,999	39 (14.7%)
	80,000–99,999	43 (16.2%)
	100,000 and above	97 (36.6%)
	Chose not to answer	22 (8.3%)
Parent 1*	No college/university	65 (25.2%)
	College/university degree	99 (38.4%)
	Training beyond college and university/ Graduate or professional degree	94 (36.4%)
Parent 2	No college/university	77 (37.7%)
	College/university degree	62 (30.4%)
	Training beyond college and university/ Graduate or professional degree	65 (31.9%)

*The actual questions in the questionnaire included seven categories: 1, Some grade school | 2, Some high school | 3, High school diploma or GED | 4, Some college/university or 2-year degree | 5, 4-year college/university graduate | 6, Some school beyond college/university | 7, Graduate or professional degree. We combined 1–3 for no college/university, 4–5 for College/university degree, and 6–7 for training beyond college/university and graduate or professional degree.

Demographics and pre-existing symptom severity

The CRISIS_AFAR questionnaire (www.crisissurvey.org/crisis-afar/) was used to obtain parent reports of child age, sex, and household income. Pre-existing symptom severity from other measures (Supplementary Table 1) was available in the comparable six MH measures at the latest time point before lockdown and was used to examine its effect on MH changes during the pandemic (Supplementary Table 1). In the entire sample, non-normal data were transformed using square-root transformation. Then, the data were standardized to Z-scores and averaged in internalizing and externalizing symptom domains.

Parental mental health

Brief versions of Patient Health Questionnaire (22) and General Anxiety Disorder (23) were used. The data were also standardized to Z-scores and summed to represent parental MH.

COVID-related factors

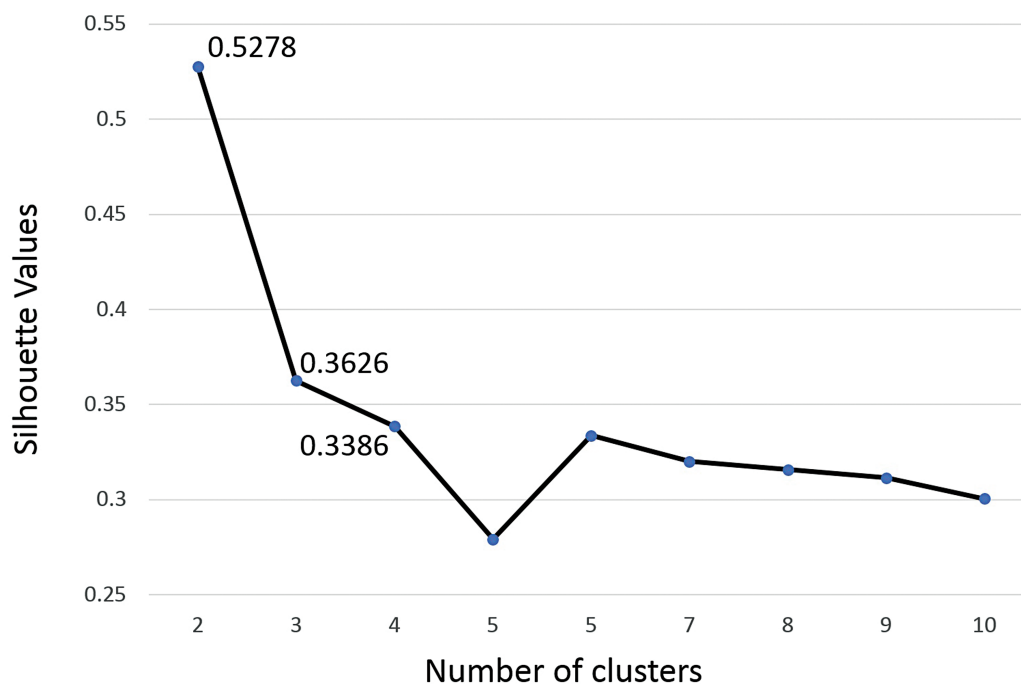
Parent and child reported perceived COVID stress was assessed in four questions and material deprivation during the pandemic in five questions, adapted from the CRISIS_AFAR questionnaire (Supplementary Table 1). The summed scores were used to represent individual levels of pandemic stress and material deprivation.

Service status conditions

Service status conditions were determined by questions regarding specific service(s) prior to emergency lockdown measures, continued service(s) following lockdown measures, or loss of service(s). Educational and health care services were categorized into academic/learning supports, psychological/social work, medical, and other allied health services (Supplementary Table 2). Children's use of acute MH services were also documented (Supplementary Table 3).

Statistical analyses

Children were grouped based on changes in MH status during the pandemic across the six MH measures described above, using K-means clustering, where each child belonged to the cluster with the nearest mean according to the Euclidian distance (24,25). We used the silhouette method to test for the optimal number of clusters. Then group memberships were examined using *t*-tests, ANOVA, and χ^2 tests, as appropriate, in child, parent, and system factors mentioned above. Lastly, we examined differences between children who did and did not access acute MH services. Benjamini–Hochberg false discovery rate correction for multiple comparisons was employed in the primary analyses (MH changes) and secondary (acute MH utilization) analyses respectively, at $P < 0.05$.



Indices of goodness of fit support 2 factor solution:

Silhouette method: 2 Clusters: 0.5278; 3 clusters: 0.3626; 4 clusters: 0.3386

Calinski-Harabasz method: 2 Clusters: 150.7545; 3 clusters: 108.0362; 4 clusters: 85.825

Figure 1. Silhouette method was used to determine the optimal number of clusters. This method computes silhouette coefficients, which range –1 to 1 and usually higher values indicates best fit. Our results demonstrated the optimal number of clusters was two.

RESULTS

Participant demographics are shown in Table 1.

Primary analyses

Mental health status changes

After removing participants who had missing data in any of six MH domains, the sample size for this analysis was 230 autistic children. The optimal clustering solution grouped children into two clusters (Figure 1). The first cluster (N=141) was identified as experiencing MH deterioration across all six MH measures, particularly in mood, irritability and ADHD symptoms. The second cluster (N=89) was identified as an unchanged group as the mean scores in all six MH measures remained mostly unchanged (Figure 2). Group characteristics are summarized in Table 2. Children and youth in the MH deterioration group had higher pre-COVID internalizing symptom severity along with parents with more MH challenges. Both they and their parents experienced high levels of COVID stress, as well as high levels of material deprivation. Notably, MH deterioration was associated with academic and medical services loss, although marginally after multiple comparison correction. A total of 61.3% of children who did not receive pre-pandemic academic services and 70.0% of children who lost these services during the pandemic showed MH deterioration, and 70.1% of children who lost medical services (access to their doctor) were in the group with deterioration.

Secondary analysis

Acute mental health services

During the same period, 37 children (14.0%) accessed acute MH services, most often through MH service providers. Group

characteristics were summarized in Table 3 based on whether participants needed acute MH services during the pandemic. Those who did tended to have slightly worse MH during the pandemic, be older, female, from relatively lower income families, have experienced higher material deprivation during the pandemic, and significantly higher loss of academic services. These results, however, did not survive multiple comparison correction.

Exploratory analyses

In a truly exploratory fashion, we are also presenting a three-factor solution, given that clinically a small group of autistic children (N=16, 7% of sample) experienced improvements during the pandemic. The data hints at a group with less parental COVID-related stress and material deprivation, as well as better parental MH (Supplementary Table 4).

DISCUSSION

In the present study, we identified distinct MH status change profiles in autistic children. The majority demonstrated MH deterioration, whereas about one-third remained unchanged. In addition, there was some evidence that a very small number experienced improved mental health. Given that autistic children tend to exhibit high comorbidity and complex symptom profiles (26–29), MH challenges were not unexpected, but the large proportion experiencing deterioration is particularly worrisome.

Our study suggests that child-specific factors, as well as parental and societal factors contribute to such deterioration. Autistic children with higher pre-pandemic internalizing symptoms were

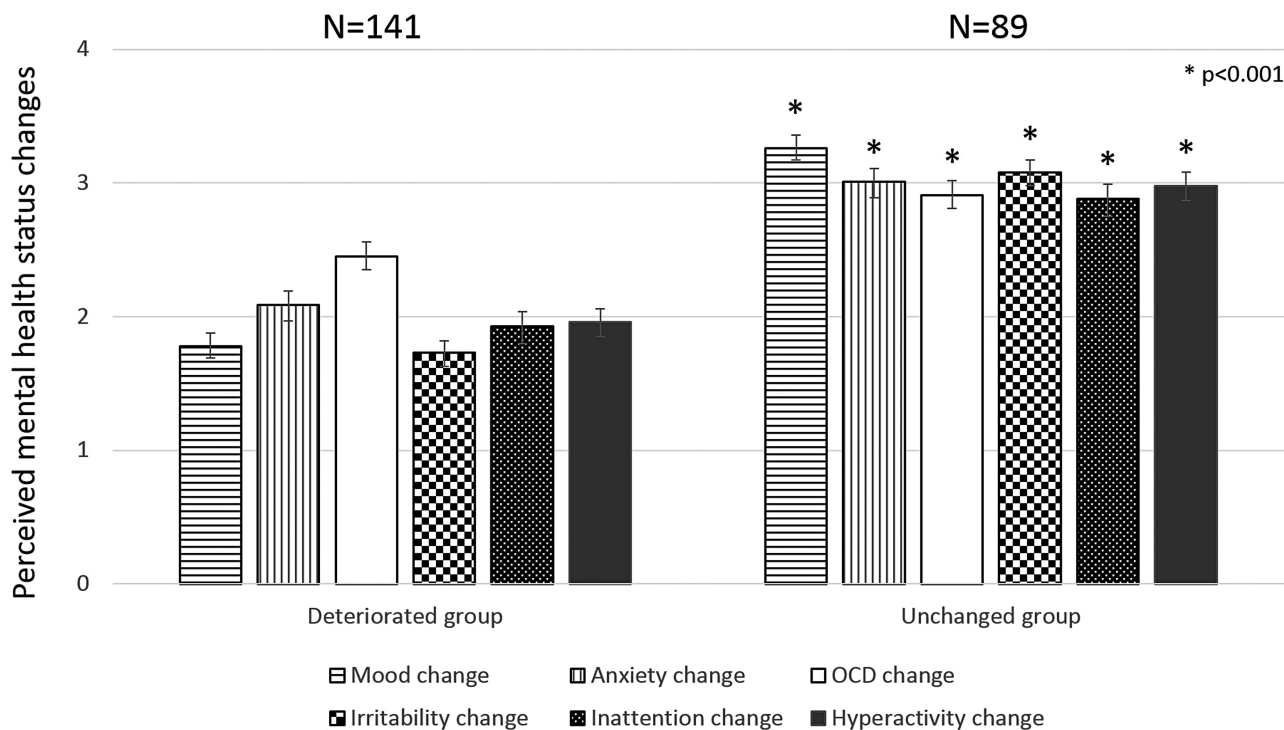


Figure 2. MH changes were examined in six measures (Mood, Anxiety, OCD symptom, Irritability, Inattention, Hyperactivity) using 5 Likert scale (1=a lot worse; 5=a lot better) (e.g., Compared to the time BEFORE the COVID-19 crisis, how is your child’s overall mood been?). Y axis represents mean scores in MH changes in each group. MH deterioration group demonstrated significantly different MH profiles across all six MH measures compared to MH unchanged group.

Table 2. Characteristics of children who experienced MH deterioration and those who did not

Variables		Deteriorated (N=141) (M/SD or N/%)	Unchanged (N=89) (M/SD or N/%)	Stats (t or χ^2)	P (P _{adjusted})	
Child mental health change*	Mood	1.78 (0.60)	3.26 (0.79)	t=-15.11	<0.001 (<0.001)	
	Anxiety	2.09 (0.72)	3.01 (0.57)	t=-10.77	<0.001 (<0.001)	
	OCD symptom	2.45 (0.66)	2.91 (0.51)	t=-5.86	<0.001 (<0.001)	
	Irritability	1.73 (0.57)	3.08 (0.66)	t=-16.39	<0.001 (<0.001)	
	Inattention	1.93 (0.71)	2.88 (0.65)	t=-10.12	<0.001 (<0.001)	
	Hyperactivity	1.96 (0.66)	2.98 (0.62)	t=-11.81	<0.001 (<0.001)	
Demographics	Child's age	10.77 (3.56)	11.56 (2.73)	t=-1.61	0.110 (0.138)	
	Child's sex [†]	Female	40 (72.7%)	15 (27.3%)	$\chi^2=3.81$	0.051 (0.072)
		Male	101 (58.0%)	73 (42.0%)		
	Household income [‡]	3.66 (1.61)	3.79 (1.55)	t=-0.56	0.579 (0.724)	
Child pre-existing symptom severity[§]	Internalizing symptom	0.21 (0.83)	-0.11 (0.81)	t=2.53	0.013 (0.023)	
	Externalizing symptom	1.04 (0.84)	0.79 (0.80)	t=1.91	0.057 (0.076)	
Parental mental health[§]	Depression and anxiety	1.26 (2.13)	-0.04 (1.74)	t=4.99	<0.001 (<0.001)	
COVID-related factors[¶]	Parent's stress	11.76 (3.13)	9.33 (3.02)	t=5.77	<0.001 (<0.001)	
	Child's stress	11.10 (3.38)	8.43 (3.21)	t=3.99	<0.001 (<0.001)	
	Material deprivation	5.64 (2.98)	4.31 (2.31)	t=-3.56	<0.001 (<0.001)	
Use of services**	Academic	Did not receive	46 (61.3%)	29 (38.7%)	$\chi^2=6.86$	0.032 (0.053)
		Continued	32 (49.2%)	33 (50.8%)		
		Lost	63 (70.0%)	27 (30.0%)		
	Psychology/ Social work	Did not receive	79 (58.1%)	57 (41.9%)	$\chi^2=0.20^{++}$	0.655 (0.728)
		Continued	12 (80.0%)	3 (20.0%)		
		Lost	50 (63.3%)	29 (36.7%)		
	Medical	Did not receive	26 (53.1%)	23 (46.9%)	$\chi^2=6.53$	0.038 (0.058)
		Continued	40 (54.1%)	34 (45.9%)		
		Lost	75 (70.1%)	32 (29.9%)		
	Allied health	Did not receive	32 (58.2%)	23 (41.8%)	$\chi^2=0.035$	0.983 (0.983)
		Continued	27 (60.0%)	18 (40.0%)		
		Lost	48 (59.3%)	33 (40.7%)		
Acute care	Did not access	123 (61.5%)	77 (38.5%)	$\chi^2=0.025$	0.875 (0.921)	
	Accessed	18 (60.0%)	12 (40.0%)			

*Mental health changes were examined in six measures (Mood, Anxiety, OCD symptom, Irritability, Inattention, Hyperactivity) using 5 Likert scale (1=a lot worse; 5=a lot better) (e.g., Compared to the time BEFORE the COVID-19 crisis, how is your child's overall mood been?)

†Per cent was calculated in the rows.

‡The survey criteria were scaled between 1 and 6 except 'Choose not to answer' (1, < 29,999 | 2,30,000–49,999 | 3,50,000–74,999 | 4,80,000–99,999 | 5,100,000–199,999 | 6, >200,000 | 9, Choose not to answer). This was assumed as an ordinal scale and the mean and SD were presented in the table.

§In each scale, non-normal data were transformed first, and then normalized and averaged across the variable categories.

¶Questions in CRISIS-AFAR were summed up and used to represent stress level of parent and child and material deprivation.

**Per cent was calculated in the rows.

††Children who did not receive the psychology/social work services before the pandemic and who continued the services during the pandemic were combined for statistical test due to a cell counted less than 5.

particularly vulnerable, while parental factors such as worse parental MH, and parental COVID-related stress were also strongly associated with greater deterioration. System/societal factors including material deprivation and loss of access to medical care and academic supports contributed to deterioration in MH. A paediatrician should be aware of and advocate for opportunities for intervention at individual, family and systems levels. This includes:

- (a) identifying internalizing symptoms in youth with ASD as this seems to be a risk factor for worse MH outcomes; these youth likely need better support to get through this pandemic and other disruptive events.

- (b) addressing parental MH as this impacts child MH.
 (c) employing strategies that maintain access to school supports for children with ASD as school closures impact not only educational outcomes (30,31) but also children's MH by disrupting various services provided through school setting.
 (d) most importantly, supporting community-wide interventions targeting family wellness, decreasing stress and preventing material deprivation.

Our exploration of factors associated with autistic children utilizing urgent MH services suggest that older females, those with material deprivation concerns and those who lost learning

Table 3. Characteristics of children who did and did not access acute mental health services during the pandemic

Variables		Did not access acute MH services (N=228) (M/SD or N/%)	Did access acute MH services (N=37) (M/SD or N/%)	Stats (t or χ^2)	P (P _{adjusted})	
Child mental health change*	Mood	2.37 (0.97)	2.33 (1.08)	t=0.18	0.854 (0.901)	
	Anxiety	2.48 (0.77)	2.26 (1.00)	t=1.16	0.253 (0.534)	
	OCD symptom	2.66 (0.58)	2.44 (0.91)	t=1.33	0.192 (0.456)	
	Irritability	2.24 (0.88)	2.34 (1.00)	t=-0.63	0.530 (0.671)	
	Inattention	2.34 (0.83)	2.14 (0.98)	t=1.35	0.179 (0.486)	
	Hyperactivity	2.33 (0.80)	2.41 (0.93)	t=-0.50	0.621 (0.737)	
Demographics	Child's age	10.63 (3.25)	12.54 (4.32)	t=-2.81	0.005 (0.095)	
	Child's sex [†]	Female	51 (79.7%)	13 (20.3%)	$\chi^2=3.20$	0.074 (0.281)
		Male	177 (88.5%)	23 (11.5%)		
	Household income [‡]	3.82 (1.55)	3.12 (1.53)	t=2.43	0.016 (0.152)	
Child pre-existing symptom severity[§]	Internalizing symptom	0.06 (0.85)	0.14 (1.04)	t=-0.41	0.683 (0.763)	
	Externalizing symptom	0.95 (0.84)	0.97 (0.78)	t=-0.09	0.926 (0.926)	
Parental mental health[§]	Depression and anxiety	0.62 (2.08)	1.01 (2.08)	t=-1.06	0.289 (0.549)	
COVID-related factors[¶]	Parent's stress	10.54 (3.25)	11.11 (3.42)	t=-0.99	0.325 (0.561)	
	Child's stress	9.84 (3.45)	10.50 (3.68)	t=-0.76	0.447 (0.708)	
	Material deprivation	4.85 (2.75)	5.95 (2.73)	t=-2.25	0.025 (0.119)	
Service loss^{**}	Academic loss	Not true	149 (65.4%)	$\chi^2=5.12$	0.024 (0.152)	
		True	79 (34.6%)			
	Psychology/Social work	Not true	156 (68.4%)	$\chi^2=2.95$	0.086 (0.272)	
		True	72 (31.6%)			
	Medical	Not true	125 (54.8%)	$\chi^2=0.49$	0.484 (0.657)	
		True	103 (45.2%)			
Allied health	Not true	117 (52.5%)	$\chi^2=0.55$	0.457 (0.668)		
	True	106 (47.5%)				

*Mental health changes were examined in six measures (Mood, Anxiety, OCD symptom, Irritability, Inattention, Hyperactivity) using 5 Likert scale (1=a lot worse; 5=a lot better) (e.g., Compared to the time BEFORE the COVID-19 crisis, how is your child's overall mood been?)

[†]Per cent was calculated in the rows.

[‡]The survey criteria were scaled between 1 and 6 except 'Choose not to answer' (1, < 29,999 | 2,30,000–49,999 | 3,50,000–74,999 | 4,80,000–99,999 | 5,100,000–199,999 | 6, >200,000 | 9, Choose not to answer). This was assumed as an ordinal scale and the mean and SD were presented in the table.

[§]In each scale, non-normal data were transformed first, and then normalized and averaged across the variable categories.

[¶]Questions in CRISIS-AFAR were summed up and used to represent stress level of parent and child and material deprivation.

^{**}Per cents were calculated within the columns.

supports, were more likely to access such services. Socially disadvantaged groups have been reported to experience more MH challenges during the pandemic (32–34), consistent with our data. Loss of academic supports and material deprivation were associated with both overall MH deterioration and acute MH service use; integrating health, education and social/community systems are critical opportunities for systems intervention.

Lastly, for a small group of children, positive parent MH and lack of financial concerns was associated with improved child MH. Although this is only exploratory work, it highlights that getting better or worse is not simply a function of underlying illness severity. Consistent with transdiagnostic insights during the pandemic from our group (4), and previous literature in ASD (31), the finding suggests that the whole family needs support, and that interventions at the population level to support wellness and low financial insecurity may be as important as mental health interventions to support optimal MH outcomes.

Limitations of the study include the relatively small sample size that may have obscured important but small associations and may

be responsible for our inability to explore children who demonstrated improved MH in a more robust fashion. The number of clusters that can be observed was limited by the sample size, which is why that third cluster is worth noting, despite the better model fits under the two-cluster model. In addition, we did not have data on the trajectory of children before the pandemic and cannot rule out that those who deteriorated were already on a declining course.

In conclusion, more than half of autistic children experienced mental health deterioration during the pandemic, and person-specific, parent- and system-level characteristics were associated with such deterioration, and may present opportunities for future interventions.

SUPPLEMENTARY DATA

Supplementary data are available at *Paediatrics & Child Health* Online by searching for pxb111.

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