



ORIGINAL ARTICLE

Impact of the COVID-19 pandemic on the well-being of children with neurodevelopmental disabilities and their parents

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Aims: To examine the impact of COVID-19 pandemic on child mental health and socio-emotional and physical well-being (including sleep, diet, exercise, use of electronic media; care giver perceptions of symptoms of child neurodevelopmental disability [NDD] and comorbidities), and care giver mental health and well-being, social support and service use.

Methods: An online cross-sectional self-report survey was distributed via disability service providers and support groups. Care givers of children aged 2–17 years with a NDD were invited to respond to questions on child symptom severity and well-being, parent well-being and service access and satisfaction.

Results: Overall, 302 care givers (94.7% female) completed the survey. Average child age was 9.7 years and 66.9% were male. Worsening of any child NDD or comorbid mental health symptom was reported by 64.5% of respondents and 76.9% reported child health and well-being was impacted by COVID-19. Children were viewing more television and digital media (81.6%), exercising less (68.0%), experiencing reduced sleep quality (43.6%) and had a poorer diet (32.4%). Almost one fifth (18.8%) of families reported an increase in the dosage of medication administered to their child. Parents reported COVID-19 had impacted their own well-being (76.1%). Over half of respondents were not satisfied with services received during COVID-19 (54.8%) and just 30% reported that telehealth works well for their child.

Conclusion: Targeted interventions are required to address worsening child neurodevelopmental disability, mental health symptoms and poor diet, sleep and exercise patterns. Improved access to telehealth services is indicated, as is further research on barriers and enablers of effective telehealth services.

Key words: child well-being; family health; neurodevelopmental disorder.

What is already known on this topic

- 1 Health and wellbeing of children is adversely impacted by the COVID-19 pandemic.
- 2 The impact on children with neurodevelopmental disabilities (NDDs) is unclear.

What this paper adds

- 1 Children with NDDs are struggling as a result of the COVID-19 restrictions, with adverse impacts on NDD symptoms, stress, health and well-being.

The COVID-19 pandemic has had significant psychological and health impacts on the global population.¹ The increased stress and anxiety associated with acquiring the life-threatening disease is further compounded by loneliness and enforced social isolation

of quarantine, particularly in children and adolescents.² Research from past pandemics has found that these disease-containment responses can be traumatising to a significant proportion of children and parents.³ Children with neurodevelopmental conditions, such as attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy (CP), intellectual disability, Tourette syndrome and rare genetic disorders (henceforth referred to as children with neurodevelopmental disabilities or NDD), may be particularly vulnerable to stress due to significant changes in routines and service access. Changes include the inability to attend schools, and a reduction in the availability of formal and informal supports, including limited contact with close or extended family members.

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The impact of these stressors may include increases in emotional arousal, impulsivity, anxiety, mood swings, aggression and sleep disturbance in children with NDDs.⁴ In addition to these direct mental health impacts, it is expected that the lack of opportunities for physical activity coupled with increased screen time due to quarantine may have an indirect impact on the health and well-being through obesity and sleep problems.^{5,6} Recent evidence also suggests worsened parental well-being, with an increased risk for mental illness, domestic violence and child maltreatment during the pandemic, especially for families with children and adolescents with special needs or vulnerabilities.⁷ In a UK study of parents of children (5–18 years old) with special educational needs and disabilities, most parents and children reported experiencing loss, worry and changes in mood and behaviour consequent to the rapid social changes linked to the COVID-19 pandemic.⁸

Changes in service delivery, including health care, during a pandemic may pose additional challenges in addressing the routine health needs of children⁹ which is expected to be exaggerated in children with NDDs. As health services close down non-critical aspects of delivery, children are likely to miss out on access to standard care such as routine health checks. Families may also be reluctant to attend health facilities for fear of exposure to COVID-19 or due to reluctance to be a burden on already-stretched health services. This may bring unintended consequences such as families increasing child medication dosage without medical input or monitoring. Substantial reductions in the availability of therapeutic supports conventionally delivered through face-to-face sessions (e.g. behavioural interventions) are also likely to adversely impact children with NDDs and their parents.

Although emerging evidence links the pandemic with increased levels of anxiety and depression for the general population,¹⁰ its effect on the health and well-being for children with NDDs, their parents and the service response are limited. It is therefore important to understand the specific impact of COVID-19 on children with NDD, including whether the pre-existing symptoms are worsening, and the way families are responding, and the impacts on service use.

This study will address this knowledge gap, with an overall aim to examine the impact of COVID-19 pandemic on the health and well-being of children with NDDs and their care givers, and impact on service use. Our specific objectives are to examine the impact of COVID-19 pandemic on

- Child mental health and socio-emotional and physical well-being (including sleep, diet, exercise, use of electronic media; care giver perceptions of symptoms of child NDD symptoms and comorbidities).
- Care giver mental health, well-being and social support.
- Service use and satisfaction

Methods

Care givers of children aged 2–17 years with a NDD were invited to complete an anonymous cross-sectional self-report survey. The online questionnaire was developed by the investigators and included study-specific, fixed-response questions. The survey questions were pilot tested with clinicians, researchers, and a small group of parents ($n = 20$). Adjustments were made to the survey based on their feedback. The survey included socio-

demographic questions about the child (age, sex, culturally and linguistically diverse background) and parent (relationship to child, single-parent household, employment, urban vs. rural location). The survey was promoted via disability service providers and support groups by emailing parents on their mailing lists with information about the study and the link to the survey, or by posting an advertisement with the link on social media. Interested parents could read the Participant Information Statement online and complete the survey *via* Research Electronic Data Capture (REDCap), a secure web-based survey tool.^{11,12} Consent to participate was considered implied if parents elected to complete the survey. The survey was open for a period of approximately 6 weeks during May and June 2020. Questions covered the following topics:

Child symptom severity and well-being

Care givers were asked to report their child's NDD diagnosis/es (e.g. ADHD, ASD, CP, intellectual disability, rare genetic condition, Tourette syndrome) along with any diagnosed comorbid mental health conditions (e.g. anxiety, obsessive compulsive disorder, behaviour). For each condition, parents/care givers indicated how much their child's symptoms changed from before the pandemic to when the pandemic was at its worst on a 5-point scale with 1 'symptoms much improved', 2 'symptoms somewhat improved', 3 'symptoms the same', 4 'symptoms somewhat worse', 5 'symptoms much worse'. Responses of 'somewhat' or 'much worse' symptoms were combined as a single 'symptoms worsened' group.

Questions encompassed the extent to which COVID-19 has impacted the child's overall health and well-being, including the following domains: (i) physical health (worsened pre-existing health conditions; reductions in sleep quality; exercise decreased; diet poorer; increased TV viewing or digital media use, increased medication use); (ii) emotional well-being (isolation stressful); and (iii) social well-being (difficulty maintaining relationships). These questions were responded to on a 5-point (1–5) Likert scale: 'strongly agree' to 'strongly disagree'. Care givers who reported 'strongly agree' or 'somewhat agree' were combined to form the 'health and well-being impacted' group.

Parent well-being

Care givers reported whether COVID-19 had impacted their well-being on a five-point Likert scale as indicated above. Care givers who reported 'strongly agree' or 'somewhat agree' were included in the impacted group.

Service access and satisfaction

Care givers responded to questions about changes to use, access, appropriateness and satisfaction with telehealth and other services on a 5-point Likert scale.

Cases were included if their diagnoses and symptom status was reported, along with basic demographic information. Descriptive statistics were completed for demographic variables (sex, age, nature of household, employment status) and participant groups (determined by the type of NDD such as ASD, CP, ADHD, Tourette Syndrome etc).

Ethical approval

All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Results

Demographic characteristics for the 302 care givers (94.7% female respondents) who completed the survey and their children with NDD are shown in *Table 1*. Male children comprised two thirds of the cohort (66.9%) and the average age was 9.7 years (range: 2–17; standard deviation: 3.8). Most children

were cared for by two care givers (81.9%). Overall, 43.5% of children had two or more siblings. There were almost equal number of participants from the metropolitan (50.7%) and from towns/rural/regional areas of Australia.

Child symptom severity and well-being

The prevalence of reported NDDs and comorbid mental health concerns is shown in *Table 2*, with 67.5% of respondents reporting more than one diagnosis for their child. The most commonly reported NDD diagnoses were ASD, ADHD and Tourette Syndrome, and the most commonly reported co-morbidity was anxiety disorder. Worsening ('somewhat' or 'much worse') of any NDD or comorbid mental health symptom was reported by

Table 1 Demographic information

	<i>n</i>	<i>n</i>	%
Sex	302		
Male		202	66.9
Female		100	33.1
Child age, mean (SD)	302	9.7	3.8
Respondent	302		
Mother		286	94.7
Father		10	3.3
Other (e.g. grandparent)		6	2.0
Lives with (number of care givers)	288		
Single care giver		52	18.1
Two care givers		236	81.9
Shared care	288	28	9.7
Have siblings	288	233	80.9
Number of siblings	230		
1		130	56.5
2		71	30.9
3		20	8.7
4–6		9	3.9
Siblings with disability	233	69	35.6
Household size	287		
2		20	7.0
3		62	21.6
4		129	45.0
5		58	20.2
6–9		18	6.3
Employment	278		
Full time		75	24.8
Part time		99	32.8
Casual		21	7.0
Home duties		57	20.8
Non-paid		26	9.4
Location	288		
City		146	50.7
Town		58	20.1
Regional		57	19.8
Rural/Remote		27	9.4
Culturally and linguistically diverse	301	35	11.6
Child has NDIS plan	250	166	66.4

NDIS, National Disability Insurance Scheme; SD, standard deviation.

Table 2 Prevalence of neurodevelopmental disabilities and comorbid mental health and worsening of the symptoms due to COVID-19 pandemic

	<i>n</i>	<i>n</i>	%
Diagnosis	302		
ADHD		118	39.1
Anxiety disorder/s		97	32.1
Autism spectrum disorder		178	58.9
Cerebral palsy		36	11.9
Depression		16	5.3
Genetic disorder		11	3.6
Intellectual disability		49	16.2
Obsessive compulsive disorder		27	8.9
Tourette syndrome		67	22.2
Rare genetic disorder		21	7.0
Other diagnosed emotional or behavioural disorder		29	9.6
Other diagnosis including physical conditions		80	26.5
Number of diagnosis selected			
1		98	32.4
2		86	28.5
3		62	20.5
>3		56	18.5
Symptom worsening			
ADHD	118	71	60.2
Anxiety disorder/s	97	67	69.1
Autism spectrum disorder	178	104	58.4
Cerebral palsy	36	15	41.7
Depression	16	8	50.0
Genetic disorder	11	1	9.1
Intellectual disability	49	18	36.7
Obsessive compulsive disorder	27	15	55.6
Tourette syndrome	67	43	64.2
Rare genetic disorder	21	2	9.5
Other diagnosed emotional or behavioural disorder	29	15	51.7
Other diagnosis including physical conditions	80	28	35.0
Worsening of any symptom	302	195	64.5

ADHD, attention-deficit/hyperactivity disorder.

Table 3 Factors impacting child's and parents physical and mental well-being

	n	n	%
Child well-being			
My child's overall health and well-being has been impacted by the COVID-19 crisis	264	203	76.9
My child has been watching significantly more TV or digital media (e.g. Netflix, YouTube, web surfing) since before COVID-19	250	204	81.6
My child's exercise has decreased as a result of COVID-19		170	68
My child has experienced reductions in sleep quality as a result of COVID-19		109	43.6
My child's diet has been poorer as a result of COVID-19		81	32.4
My child has become more easily annoyed, irritable and angry since the COVID-19 outbreak, compared to before the outbreak		157	62.8
My child has had difficulty maintaining relationships as a result of COVID-19		165	66
COVID-19 restrictions have been stressful for my child	258	189	73.3
COVID-19 has significantly disrupted my child's routines		244	94.6
Child receiving more medication than normal†	233	44	18.8
Parental well-being			
COVID-19 has had an impact on my well-being	264	201	76.1
Balancing work with childcare/family responsibilities has been difficult for me due to COVID-19	258	190	73.6
My pre-existing mental health conditions have worsened due to COVID-19		112	43.4
My pre-existing physical health conditions have worsened due to COVID-19		91	35.3
I am worried about making it through future periods of isolation		121	46.9
I am concerned about the stability of our living situation		70	27.1
Changes related to the COVID-19 crisis have created financial problems for me or my family		102	39.5
Service access and supports			
There has been a significant change in supports or services available under my child's NDIS plan since before COVID-19 (e.g. group based social activities)	149	101	67.8
Overall, I am satisfied with the services my child has received during COVID-19	229	104	45.2
Have you used telehealth services for your child during COVID-19?†	244	168	68.8
I believe that telehealth services work well for my child	230	69	30
I am satisfied with the telehealth services on offer		114	49.6
Telehealth therapy services not possible for child†	75	31	41.3
Practitioner/s are confident/competent in providing services via telehealth		121	52.8

†Response in yes/no format.

NDIS, National Disability Insurance Scheme.

64.5% of respondents. Specifically care givers of 69.1% of those with an anxiety disorder, 64.2% with Tourette Syndrome, 60.2% with ADHD and 58.4% with ASD reported worsening of symptoms.

The proportion of care givers reporting worsening of child's physical, mental and socio-emotional well-being is shown in Table 3. The child's overall health and well-being was reported to have been impacted by COVID-19 in 76.9% of respondents. In relation to child physical well-being, care givers reported ('strongly agree' or 'somewhat agree') that children were viewing more television or using digital media (81.6%), while there was a decrease in exercise (68.0%), reductions in sleep quality (43.6%) and poorer diet (32.4%). Care givers agreed (strongly or somewhat) that their children were more easily annoyed, irritable, and angry since the COVID-19 outbreak, compared to before the outbreak (62.8%), they had difficulty maintaining relationships (66.0%) and COVID-19 restrictions have been stressful for their child (73.3%). Around one in five (18.8%) of care givers reported an increase in the dosage of medication administered to their children.

Parent well-being

In terms of parent well-being, 76.1% reported that COVID-19 has had an impact on their well-being, and 73.6% reported that balancing work with childcare/family responsibilities had been an area of difficulty during the pandemic (Table 3). Worsening of a pre-existing mental health condition was reported by 43.4% of respondents while 46.9% expressed worry about making it through future periods of isolation. Around 27.1% reported being concerned about the stability of their living situation while 39.5% reported financial problems as a result of the pandemic.

Service use and satisfaction

Of the total sample, 66.4% had a National Disability Insurance Scheme plan (Table 1) with 67.8% of care givers reporting a change in supports or services available under their child's National Disability Insurance Scheme plan. Just under one half (45.2%) of the respondents said that they were satisfied with the services their children have received during the COVID-19

pandemic. While 68.8% reported using telehealth services during the COVID-19 pandemic, only 30.0% said that telehealth works well for their child. Less than half (41.3%) also reported that telehealth services for therapy were not an option for their child. Just over half (52.8%) reported that practitioners were confident and competent in providing telehealth services.

Discussion

This survey of over 300 parents found significant adverse impacts from COVID-19 on the health and well-being of children with NDDs. Close to two thirds of care givers reported that their children's NDD symptoms and comorbid mental health conditions had worsened. Social and emotional well-being were also impacted for close to three-quarters of children, with a substantial proportion of care givers reporting that the restrictions were stressful for themselves and their children. Almost one in five respondents indicated that their children took more medication during the COVID-19 pandemic. It is possible that the care givers were using increased dosages of medication to treat difficult child behaviours, although the type of medication and reasons for its use were not explored. Groups such as the European ADHD Guidelines Group recently recommended that parents should avoid increasing doses of medication (beyond those prescribed) to manage stress related to COVID-19 confinement.¹³

More than 9 in 10 care givers reported that their children's routines had been impacted by COVID-19. The impact of COVID-19 and the effects of home confinement appeared to be disrupting children's routines, which in turn was contributing to reduced sleep quality, a poorer diet, reductions in exercise and increases in time spent engaging in social media and TV. This is supported by research that has found that when children are not in school, they are less likely to be physically active, have poorer sleep and spend more time engaging with digital media.¹⁴ This finding is of special relevance as the importance of maintaining good diet, sleep and physical activity during the pandemic has been highlighted with specific guidance for promoting physical activity developed for children with ASD.¹⁵ As noted by Prime *et al.*, change in routines due to COVID-19 may increase demands on care givers to develop new routines for their children.¹⁶ It is also noteworthy that over one third of respondents reported that children had a sibling with a disability, which would add to parental stress in managing household duties and daily routines. In addition, balancing work with childcare/family responsibilities was reported to be difficult for almost three-quarters of care givers, making it more challenging for them to establish and adhere to new routines.

Three-quarters of care givers reported their well-being was impacted by COVID-19, with worsening of mental health reported by close to half (43.4%) and physical health over a third (35.3%) of care givers. These impacts may be due to home confinement, balancing work/family needs, or having to care for the needs of other family members. This may be compounded by infection fears, frustration, boredom, insufficient medical supplies, inadequate information etc. Furthermore, 39.5% of care givers reported that changes related to the COVID-19 crisis have created financial problems for their family. This is concerning given the recent finding that significantly more Australian

children may become vulnerable as a result of COVID-19-related family unemployment and underemployment.¹⁷

As a response to COVID-19, many service providers have made a rapid transition towards telehealth services, yet it appears from this study that these services were either unavailable, not feasible or ineffective for some children with NDDs. This survey found low care giver ratings of effectiveness, satisfaction, and practitioner confidence with telehealth services received. There are a number of service implications resulting from these findings. Firstly, it is essential that there is ongoing service delivery for children and families, especially in the event of future lockdowns. This includes providing families with technological support; training of practitioners in the effective use of telehealth services for children with NDD; and ensuring safe face-to-face models of care when required. Further, research into the barriers and enablers associated with effective telehealth service delivery for children is also urgently required. Finally, given the impact of COVID-19 on child and care giver well-being, targeted services supporting children with NDDs and their families are clearly needed. These could focus on strategies for helping care givers establish routines, improve child sleep, diet and exercise, and limit screen time, along with behavioural parent management strategies for managing challenging behaviours.¹³

There are a number of limitations that should be taken into account in interpreting the findings of the study. First, the data presented in this study were derived from a cross-sectional survey that was only available online. Therefore, the results may not be representative of families who do not access online content or have adequate English language proficiency to do so. Further, some parents may have been unable to complete the questionnaire due to overwhelming care and work responsibilities. While a number of disability service providers and support groups with national coverage circulated the survey to parents within their networks, there is a risk of selection bias which impacts the generalisability of the survey results. For example, half our sample included parents living in rural and remote areas whereas only approximately 30% of the Australian population reside in these areas.¹⁸ However, we regard this as a strength of the research as surveys typically fail to include an adequate representation of rural and remote families. In view of this possible selection bias, our findings may underestimate the extent of difficulties experienced by parents of children with NDD during the pandemic, as those experiencing more difficulties may have been too time poor, disadvantaged or lacked access to technology to complete the survey. Second, the survey was distributed at a time when state governments within Australia had started easing restrictions, with further easing imminent in most states. Given this timing, it is possible that in many families, child and care giver well-being may have improved compared to the initial height of the pandemic in April/May. Finally, a limitation of the survey is that it did not collect information, such as the types of medications that were subject to increased dosages during the pandemic, that would assist with interpretation of results.

Conclusion

Children with NDDs rely on systems of support, including families, services, and support workers. The results of this survey highlight the breakdown of these systems of support and the

significant disruption to home, family and social support networks, and the associated impact on the mental health and well-being of both children with NDDs and their care givers. Our findings suggest that worsening of mental health symptoms, particularly in those with anxiety and ADHD, was coupled with poor diet, sleep and exercise patterns for many children, which would benefit from targeted interventions. Further, telehealth services appear to have been ineffective for many children with NDDs. Improved access to and coordination of health services – using hybrid models of telehealth and face-to-face delivery – is indicated.

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