



SHORT REPORT

Neurodisability care in the time of COVID-19

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Abstract

Background: The COVID-19 pandemic resulted in an unprecedented societal and healthcare global crisis. Associated changes in regular healthcare provision and lifestyle through societal lockdown are likely to have affected clinical management and well-being of children/young people with neurodisability, who often require complex packages of multidisciplinary care.

Methods: We surveyed 108 families of children/young people with severe physical neurodisability and multiple comorbidities to understand how the pandemic had affected acute clinical status, routine healthcare provision, schooling and family mental and social well-being.

Results: A significant proportion of families reported missing hospital appointments and routine therapy, with subsequent worsening of symptoms and function. Families additionally described worsening stress and anxiety during the pandemic, regardless of their baseline level of socio-economic deprivation.

Conclusion: This highlights the profound effect of the COVID-19 pandemic on health and function in young people with severe neurodisabilities and emphasizes the clear need to better understand how to support this vulnerable population moving forwards.

KEYWORDS

clinical guidelines, COVID-19, family support, neurodisability

1 | INTRODUCTION

The rapid emergence of the coronavirus disease (COVID-19) pandemic of 2020 resulted in an unprecedented societal and healthcare global crisis. In the United Kingdom, while much of the pandemic response was understandably focused on reducing general population transmission and mortality in vulnerable groups such as the elderly or immune compromised, little attention or resource was directed towards meeting the ongoing needs of the ~1 million children/young people living with disabilities. This is of clear importance as these children frequently require complex packages of multidisciplinary care including regular hospital assessments and procedures, in addition to the educational and social development needs common to all children (Brenner et al., 2018; Carter et al., 2021; Orben & Blakemore, 2020).

Two specific aspects of the COVID-19 pandemic and its associated response are particularly relevant to this population: prioritization and reallocation of limited healthcare resources and the household 'lockdown' period(s) imposed to limit general spread of infection and protect high-risk groups.

The rapid spread of infection, coupled with the acute and severe nature of COVID-19 in specific populations (such as the elderly and those with coexisting chronic medical conditions) resulted in unparalleled strain on healthcare resources (Emanuel et al., 2020). This included total saturation of intensive care facilities and overwhelmed clinical staff, many of whom were redeployed from their usual roles to assist in the care of COVID-19 patients (Emanuel et al., 2020). To enable prioritization of critical care services and further reduce risk of cross-infection, the majority of elective hospital admissions and

surgery/procedures were cancelled or postponed. Scheduled outpatient consultations were also either reorganized to be done remotely or cancelled entirely.

These changes in healthcare provision were of particular relevance to children/young people with severe physical neurodisability, as those with cerebral palsy (CP), for example, represent 0.3% of the population yet account for five times more hospital admissions and outpatient appointments, with rates increasing further for those with more severe difficulties (Carter et al., 2020). Many children/young people with severe neurodisability have comprehensive therapy needs due to their heterogenous patterns of difficulties encompassing not only motor/physical impairments but often also affecting the cognitive and communicative domains (Brenner et al., 2018; Carter et al., 2020).

The UK government implemented an initial population-wide lockdown on 23 March 2020, with additional instructions for the clinically vulnerable to stay 'shielded' entirely in their homes with no trips outside and no access to external visitors. Although essential to reduce spread of infection and mortality, such lockdown measures have also inevitably been associated with adverse consequences on household finances, psychological well-being and general health (Orben & Blakemore, 2020). School closures additionally caused children/young people to lose not only a substantial amount of education but also the social and developmental benefits of associating with peers and wider society. This is of additional concern as social isolation during this critical period of neuroplasticity can have long-lasting negative consequences on brain development and organization, when there is also a heightened vulnerability to mental health disorders (Orben & Blakemore, 2020).

This short report aims to highlight the impact of the initial pandemic response on the health, education and social care provision, for children and young people with severe physical neurodisability and multiple comorbidities.

2 | METHODS

2.1 | Study design and population

A semi-structured interview questionnaire was designed by the clinical team to use with families of children/young people with severe physical neurodisability and multiple comorbidities. The questionnaire was designed as a semi-structured interview to be used by clinicians in a routine clinical consultation, rather than a research tool. The questions included a variety of open and closed questions, with some Likert rating scales, some category responses (e.g. same, worse and better) and some free text responses.

All patients were known to the regional paediatric neurodisability and complex movement disorder services at a large tertiary children's hospital and were contacted approximately 6 weeks into the UK lockdown. The questionnaire was completed either over the telephone or video as part of a scheduled outpatient consultation with their consultant or therapist and aimed to collect information about acute clinical

Key messages

- The majority of children with severe neurodisability had missed clinical appointments and had reduced therapy contact during the COVID-19 pandemic lockdown period.
- Many families described worsening of their stress and anxiety during the lockdown period, regardless of their level of socio-economic deprivation.
- It is vital we understand how to better support the vulnerable neurodisability population and avoid worsening of their pre-existing physical, mental health and socio-economic difficulties.

status, routine healthcare, schooling and participation and the mental and social well-being of the child/young person and their family. Four consultants in paediatric neurodisability, one paediatric neurologist and three physiotherapists completed the questionnaire during their consultations.

As the questionnaire was conducted as a convenience sample of those patients booked into an outpatient appointment, there was no specific inclusion criteria expect for a known diagnosis of physical neurodisability, which had necessitated referral to our tertiary-level service. Local trust approval was granted for the questionnaire and the clinician confirmed verbally with the families their consent to completing the questionnaire as part of the routine consultation. The consent and consultation was documented as part of the patient's routine medical records.

2.2 | Patient involvement

Patients were not directly involved in setting the research question or methods, although the study and questionnaire items were designed to explore particular issues highlighted through discussion with families during their routine care. Specific sections of the questionnaire were only completed if relevant to the patient and the family did not decline to discuss the specific issue covered.

3 | RESULTS

The sample consisted of 108 families of children/young people (median age 9 years old; range 0–25 years) with established neurodisability, representing the full spectrum of socio-economic deprivation (postcode derived index of multiple deprivation [IMD]: median decile 6 [range 1–10]), drawn from across five of the seven NHS England regions (see Table 1). The majority (79.6%) had a diagnosis of CP, with nearly all of those (96.5%) severely affected with level IV or V difficulties on the Gross Motor Classification Function System (GMFCS) (Palisano et al., 1997).

TABLE 1 Summary of sample population demographic information and the effects of lockdown on acute and routine healthcare provision

Demographics			
Sex (n = 108):	Male: 60 (56.6%); Female: 46 (43.4%)		
Age (median, range)	9 years old (0–25 years)		
Diagnosis	Cerebral palsy: 86 (79.6%) Other: 22 (20.4%)	GMFCS level I: 0 (0%); GMFCS level II: 0 (0%); GMFCS level III: 3 (3.5%); GMFCS level IV: 32 (37.2%); GMFCS level V: 51 (59.3%)	
Acute health			
Response to lockdown	Shielding: 76 (70.4%); self-isolating: 22 (20.4%); social distancing: 7 (6.5%); other: 3 (2.7%)		
Access to medication (n = 107)	Had difficulties: 28 (26.2%)	No difficulties 79 (73.8%)	
Ability to get urgent care	Not needed: 78 (72.2%)	Needed and able to access: 25 (23.2%)	Needed but difficult to access: 5 (4.6%)
Would they travel to hospital for treatment? (n = 101)	Yes: 66 (65.3%)	No: 35 (34.7%)	
Pain symptoms (n = 78)	Worse in lockdown: 43 (55.1%)	Same as before lockdown: 32 (41.0%)	Better during lockdown: 3 (3.9%)
Tone abnormalities (n = 106)	Worse in lockdown: 55 (52.9%)	Same as before lockdown: 45 (42.4%)	Better during lockdown: 6 (5.7%)
Epilepsy (n = 62)	Worse in lockdown: 17 (27.4%)	Same as before lockdown: 39 (62.9%)	Better during lockdown: 6 (9.7%)
Sleep difficulties (n = 89)	Worse in lockdown: 37 (41.6%)	Same as before lockdown: 40 (44.9%)	Better during lockdown: 12 (13.5%)
Routine healthcare			
Physiotherapy (n = 102)	Contact: 59 (57.9%)	No contact: 43 (42.1%)	
Occupational therapy (n = 101)	Contact: 26 (25.7%)	No contact: 75 (74.3%)	
Speech and language therapy (n = 91)	Contact: 26 (28.6%)	No contact: 65 (71.4%)	
Dietician (n = 82)	Contact: 27 (32.9%)	No contact: 55 (67.1%)	
Hospital appointments	Missed ^a : 72 (66.7%)	None missed: 36 (33.3%)	
Orthopaedic surgery (n = 72)	Cancelled: 17 (23.6%)	None missed: 55 (73.4%)	
Other surgery (n = 67)	Cancelled: 13 (19.4%)	None missed: 54 (80.6%)	

^aAppointments may have been cancelled by the healthcare provider or missed by the family due to shielding.

Pandemic-related changes in healthcare provision profoundly affected this population (see Table 1): with 66.7% missing at least one scheduled hospital appointment and a substantial number also missing planned orthopaedic (23.6%) or other (19.4%) surgery. None of the children/young people surveyed had developed acute COVID-19 symptoms or had tested positive for the illness.

In this study population, the routine provision of therapies was markedly affected by the pandemic, with all families reporting some interruption of their appointments. While many had still been able to have remote consultations with their physiotherapist (57.9%), this had been more difficult for occupational therapy (25.7%) and speech and language therapy (28.6%). Importantly, many families highlighted worsening of their child's symptoms in this period relating to pain (54.2%), tone abnormalities (50.5%) and sleep difficulties (41.5%), suggesting that even a relatively short 6-week interruption of routine, healthcare had led to rapid deterioration of both clinical symptoms and function. Of interest, a minority surprisingly also reported improvement in their child's symptoms (Table 1) during lockdown perhaps linked to positive changes in daily routine and increased parent contact.

3.1 | Wider effects on mental well-being and education

The majority of our sample had been instructed or had chosen to shield their child at home (70.4%), and only a tiny minority were sending their children to school (1.3%) (Table 2). However, interestingly, a significant proportion (65.3%) stated they were still prepared to travel to our centre for intervention if needed.

The aforementioned wider adverse effects of lockdown on mental health and family well-being are of particular relevance for our population, as it is known that many carers of children with disabilities suffer from reduced quality of life and increased rates of physical, mental health and financial difficulties in comparison to those of typically developing children (Parkes et al., 2011). Many parents in our sample reported that lockdown had not only worsened their child's stress and anxiety (20.4%) but that a far higher number reported these problems worsening for themselves (62.0%) (see Table 2). While socio-economic deprivation significantly related to perceived worsening of family financial circumstances and food provision (multinomial logistic regression, $P < 0.05$), we found it did not relate to any other

TABLE 2 Summary of the effects of lockdown on well-being and education in children and young people with complex neurodisability

Child/young person and family well-being			
Parental stress and anxiety	Worse in lockdown: 67 (62.0%)	Same as before lockdown: 41 (38.0%)	Better during lockdown: 0
Parental health	Worse in lockdown: 26 (24.0%)	Same as before lockdown: 82 (76.0%)	Better during lockdown: 0
Family financial concern ^a	Worse in lockdown: 16 (14.8%)	Same as before lockdown: 90 (83.3%)	Better during lockdown: 2 (1.9%)
Food provision difficulties ^a (n = 107)	Worse in lockdown: 24 (22.4%)	Same as before lockdown: 81 (75.7%)	Better during lockdown: 2 (1.9%)
Child stressed or anxious	Worse in lockdown: 22 (20.4%)	Same as before lockdown: 78 (72.2%)	Better during lockdown: 8 (7.4%)
Education			
Type of regular schooling (n = 103)	Special school: 77 (75.5%); mainstream 5 (4.9%); normally homeschooled 4 (3.9%); not in school: 16 (15.7%)		
Schooling during lockdown (n = 76)	Homeschooling: 75 (98.7%); attending school 1 (1.3%)		
Child is reported to be 'missing' school (n = 87) ^b	Yes: 45 (51.7%)	No: 42 (48.3%)	

^aSignificant relationship ($P < 0.05$) with postcode defined index of multiple deprivation (IMD) decile as tested with multinomial logistic regression.

^bParents were asked subjectively if they thought that their children were 'missing' school either from a socio-emotional point of view or with respect to implied deterioration in physical or mental well-being.

features of healthcare provision or mental well-being, thus suggesting that difficulties were common to all families regardless of their socio-economic status.

4 | DISCUSSION

Although we acknowledge that there are clear limitations to our study design and in particular with the use of questionnaires based on retrospective parent report, the findings from interviewing our regional centre sample suggest that the COVID-19 pandemic and its associated lockdown have profoundly affected the lives of vulnerable young people with severe neurodisabilities and their families. These data are consistent with and add to the many contemporaneous anecdotal reports in the media of the considerable difficulties that patients and families with disabilities have faced. Subsequent to the initial submission of this manuscript in summer 2020, there have been multiple other publications on the impact of the lockdown on the health of all children and young people, typically developing, those with neurodevelopmental disorders and physically disabled (Couper-Kenney & Riddell, 2021; Heyman et al., 2021; Nonweiler et al., 2020).

5 | CONCLUSION

This study emphasizes the importance of their regular care packages for children with severe physical disabilities and demonstrates how losing even a few weeks can have a marked effect on health, participation and function. As healthcare services continue to adjust in light of the ongoing pandemic, it is vital we understand how to support our vulnerable neurodisability population through effective remote healthcare provision, systems to prioritize and safely perform hospital

interventions and put robust measures in place to identify and avoid worsening of the physical, mental health and socio-economic challenges they face.

DATA AVAILABILITY STATEMENT

As the data consists of clinical and sociodemographic information collected through reviewing NHS records, it is not possible to openly share the data in an anonymized form. However, the authors are happy to be contacted to share specific aspects of the data on request if it can be appropriately anonymized.

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