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**Original Article**

# Original Article

# Mental health impacts of the COVID-19 pandemic on children with underlying health and disability issues, and their families and health care providers

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## ABSTRACT

**Objectives:** The COVID-19 pandemic has impacted mental health at a population level. Families of children with health vulnerabilities have been disproportionately affected by pandemic-related policies and service disruptions as they substantially rely on the health and social care system. We elicited the impact of the COVID-19 pandemic on children with health and disability-related vulnerabilities, their families, and their health care providers (HCPs).

**Methods:** Children with diverse health vulnerabilities (cardiac transplantation, respiratory conditions, sickle cell disease, autism spectrum disorder, mental health issues, and nearing the end of life due to a range of underlying causes), as well as their parents and HCPs, participated in semi-structured interviews. Data were analyzed using qualitative content analysis in determining themes related to impact and recommendations for practice improvement.

**Results:** A total of 262 participants (30 children, 76 parents, 156 HCPs) were interviewed. Children described loneliness and isolation; parents described feeling burnt out; and HCPs described strain and a sense of moral distress. Themes reflected mental health impacts on children, families, and HCPs, with insufficient resources to support mental health; organizational and policy influences that shaped service delivery; and recommendations to enhance service delivery.

**Conclusion:** Children with health vulnerabilities, their families and HCPs incurred profound mental health impacts due to pandemic-imposed public health restrictions and care shifts. Recommendations include the development and application of targeted pandemic information and mental health supports. These findings amplify the need for capacity building, including proactive strategies and mitigative planning in the event of a future pandemic.

**Keywords:** COVID-19; Health challenges; Mental health; Paediatric; Pandemic.

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The COVID-19 pandemic has resulted in heightened anxiety, isolation, and emotional and/or behavioral challenges for children with health vulnerabilities, as illustrated among children with cystic fibrosis (1), autism (2–4), and mental health challenges (5,6). Impacts have been attributed to fears about COVID-19 risk (7), decreased social contact (8,9), and fewer supports (8,9). Online/telehealth services have resulted in decreased stress for families (8) (e.g., reduced travel to appointments), yet heightened mental health challenges due to shifts such as less in-person engagement (8,9). Service delivery shifts have resulted in health care provider (HCP) concern about quality of care (10). Despite growing knowledge about COVID-19, more research is needed to illuminate how the pandemic has impacted children with health vulnerabilities and their families. This study explored the psychosocial and service delivery impacts of the COVID-19 pandemic on paediatric populations in two Canadian provinces (Alberta and Ontario). It examined the care journey and experiences of children, parents, and HCPs across disparate conditions: autism, mental health conditions, cardiac transplantation, respiratory challenges, sickle cell disease, and terminal illness due to a range of underlying conditions.

## METHODS

Children, their parents, and HCPs were recruited across the above paediatric populations (April 2020 to June 2021). Participating children (≤18 years) and their families who received inpatient and/or outpatient care during the COVID-19 pandemic in the community or paediatric hospital settings were interviewed (sample details in Table 1). For the end-of-life cohort, bereaved parents were recruited ≥6 months after the child's death. HCPs were eligible to participate if they had provided patient care during the pandemic. Participants were initially informed about the study by a local HCP and if willing to share their contact information, this was shared with the research team. If a given participant was willing to participate, informed consent was obtained, and the interview proceeded. For children, both child and parental consent were obtained.

Individual interviews with children and families, and individual or group interviews with HCPs, were conducted, audio-recorded, and transcribed verbatim for analysis. Interviews were facilitated by DN, GD, RZ, and OC, along with trained research assistants who were closely supervised by the investigators. Interviews were convened via telephone or video-conferencing technology at a convenient time for participants. Interviews were guided by a semi-structured schedule with open-ended questions eliciting participants' experiences of the pandemic and perceived impacts on processes of care (see examples of interview questions in Table 2), with questions slightly tailored for participant group (e.g., children, parents, HCPs, and particular populations). The interview initially provided structured questions to elicit contextual information (e.g., child/family health background, HCP role, demographics, etc.). Open-ended questions then focused on research areas such as how the pandemic was perceived to have affected children's care. Most child participants opted to be interviewed with their parents. Institutional ethics review board approval was obtained from host universities/hospitals prior to study commencement.

Transcripts were analyzed by an inductive content analysis approach (11–13), reflecting steps of reading and re-reading transcripts for units of textual meaning (codes), organization of the codes in categories, and determining underlying meanings in generating themes (11,12). Analysis was supported by NVivo 12 qualitative data analysis and management software. Methodological rigor was demonstrated through review of emergent themes against raw data for verification, theme review by participants and clinical experts for corroboration, and referential adequacy, which entails incorporating text quotes to verify emergent themes (11–15).

**Table 1.** Demographic information about child and parent participants

| Paediatric subgroup | # of children interviewed | # of parents interviewed (age range of children) | Ethnicity (self-reported) | Child condition |
|---|---|---|---|---|
| Autism spectrum disorder | 3 | 12 (8–16 years) | Canadian, European, Somali, First Nation, Latino | Autism, Autism and Intellectual Disability |
| Cardiac transplant | 2 | 15 (1–16 years) | Canadian, Indigenous, Filipina | Cardiac Transplant, Cardiac Transplant and Cerebral Palsy, Cardiac Transplant and Anxiety |
| Mental health issues | 19 | 23 (13–18 years) | Canadian, European, Asian, Caribbean | Anorexia Nervosa, Anxiety and Depression, Anxiety, Major Depressive Disorder and Body Dysmorphia, Anorexia Nervosa and Anxiety, Unspecified Eating Disorder and Depression, Anxiety and Gender Dysphoria |
| Respiratory conditions | 4 | 12 (16 months–16 years) | Canadian, European; Indigenous, Black | Asthma, Asthma and Seasonal Allergies, Asthma and Global Developmental Delay, Interstitial Lung Disease, Cystic Fibrosis |
| Sickle cell disease | 2 | 11 (21 months–18 years) | Canadian, African, Jamaican | Sickle Cell Disease, Sickle Cell Disease and Blood Conditions, Sickle Cell Disease and Narcolepsy |
| End-of-life | n/a | 3 (n/a) | Canadian, African, European | Cancer, Brain Tumor, Cardiac Condition, Premature Birth |
| TOTAL | 30 | 76 | | |

## RESULTS

A total of 262 participants were interviewed (30 children, 76 parents, and 156 HCPs; see demographic information in Tables 1 and 3). While the pandemic has been difficult for the general population, findings revealed unique and deleterious impacts on children with health vulnerabilities, their families, and HCPs. Themes were as follows: (i) changes in daily life impacting family mental health, (ii) a lack of resources, with further negative impacts on mental health, (iii) mental health challenges among HCPs, (iv) organizational and policy influences shaping service delivery, and (v) recommendations to enhance service delivery. Table 4 exemplifies text quotes related to each of the following themes.

**Table 2.** Examples of common interview questions across groups*

| For families | For health care/service providers |
|---|---|
| • How did the COVID-19 pandemic affect you/your child?<br>• How did you/your child's health care change or stay the same during the COVID-19 pandemic?<br>• How did the COVID-19 pandemic affect the support you and your family received?<br>• What was it like to be in the hospital during the COVID-19 pandemic?<br>• How was the COVID-19 pandemic made easier or harder than it could otherwise have been?<br>• What has helped you/your family get through this experience?<br>• How could care better address the needs of children and their families during a pandemic like COVID-19? | • How have children with health vulnerabilities and their families experienced the COVID-19 pandemic?<br>• How were you able to share information with families about a child's health condition or treatment during times of visitation restrictions or limited access to ambulatory or home care?<br>• How has paediatric care to this population been impacted by the pandemic?<br>• What impact has this experience had on these children and their families?<br>• What do children with health vulnerabilities and their families specifically need in their care during a pandemic?<br>• What do health care professionals need to manage in a pandemic? |

*While questions were similar between the different groups to facilitate analysis and comparison, language in the interview guide was tailored to the specific population participating in each interview.

### Changes in daily life impacting family mental health

The pandemic extraordinarily and negatively impacted many aspects of daily life for children with health vulnerabilities and their families. Challenges included shifted school and work arrangements, and diminished recreational activities and social functions such as family gatherings. Two major subthemes emerged when examining these impacts. For children/youth, isolation negatively impacted mental health. Children/youth described a lack of social engagement with peers due to physical distancing and online schooling, which led to feelings of loneliness. In some cases, choosing to remain in online school due to health vulnerabilities while peers returned to school in-person was challenging for children/youth, with some experiencing depressive symptoms. It was noted that increased isolation may have exacerbated pre-existing mental health concerns as some youth developed additional and/or worsening symptoms. This observation was most pronounced amongst youth with autism and/or pre-existing mental health challenges.

The second subtheme entailed multiple, difficult and incommensurate parental roles due to pandemic shifts. Increased stress reflected the daily management of online school along with increased caregiving responsibilities, while also maintaining obligations such as employment and other activities of daily living. Some parents described malaise and feeling burnt out because of heightened personal and family responsibilities; this was particularly challenging for families who had lost home-based supports and/or respite care.

Public health and hospital protocols were described to negatively impact family members' well-being. As an example, infection control protocols and changes (e.g., visitor restriction, mask

**Table 3.** Demographic information about health care/service provider participants

| Paediatric subgroup | Sample | Health care/Service provider role | Years of experience (range) |
|---|---|---|---|
| Autism spectrum disorder | 18 | Behavioural analyst, director, educational consultant, occupational therapist, program lead, psychiatrist, psychologist, social worker, special education teacher, speech pathologist, teacher | 1-30 |
| Cardiac transplant | 8 | Cardiologist, child life specialist, dietician nurse, heart and lung transplant coordinator, social worker | 2-36 |
| End-of-life | 25 | Cardiologist, chaplain, clinical scientist, counselor, critical care physician, nurse, oncologist, psychiatrist, social worker | 3-34 |
| Mental health issues | 98 | Clinical supervisor, dietician, educational consultant, family counsellor, intake consultant, mental health clinician, mental health therapist, nurse, nurse clinician, occupational therapist, paediatrician, physiatrist, physiotherapist, program manager, psychiatrist, psychologist, social worker, speech language pathologist | 1-35 |
| Respiratory conditions | 7 | Nurse, paediatric respirologist, paediatric respiratory therapist | 7-26 |
| TOTAL | 156 | | |

**Table 4.** Examples of interview quotes illustrating emergent themes

| Theme | Participant group | Quote |
|---|---|---|
| **General Theme 1: Changes in daily life negatively impacting family mental health** | | |
| Subtheme: 1a. Isolation | Parent | "School was his social outlet and there was a concerted effort at school to socialize him. He likes to play alongside other kids, but [now is] not with other kids. So the social side just suddenly disappeared; it was gone. And he did comment about that. He would say, 'I miss my friends', and 'I'm lonely'." |
| | Child | "I remember the first few weeks or even months [of the pandemic], how stressed and how sad I was that I wasn't able to see many people." |
| | Health care provider | "Already having a child with a disability is stressful and then, you know, now add on a global pandemic, like that would be stressful for anyone but now they had children who were in home 24 hours a day and, you know, the kids that we work with, a lot of them really thrive on routine and activity.… Having to move all of that into a home, we were trying so hard to maintain consistency with what they were doing before the pandemic, and the family was just like, you know, my kid, he doesn't do well at home." |
| Subtheme: 1b. Managing multiple roles | Parent | "That's been a challenge for me because normally when [son's] teacher would be here, she would be teaching him, but now it's like both of us (child and parent), and I'm just like, 'I can't clean the house until after school'… so I'm rushing to do what I normally would do when she would be here…. That's added stress." |
| | Health care provider | "[Given multiple demands,] some families have really gotten into depression, and we have to do a lot more supporting the mental health of families." |
| **General Theme 2: A lack of resources, with negative impacts on family mental health** | Parent | "It was very confusing. He still wanted to go to school; he didn't understand why he couldn't. Yeah, it was just a lot of like, he just kept asking about school and going, and I kept saying, 'we can't', and I tried explaining to him why, but [he] just didn't… get it." |
| | Health care provider | "There were families that voiced extreme anxiety about even just leaving the [facility] because they were so afraid of this virus [and] living in the city with their child when the virus was spreading so quickly in the community." |
| **General Theme 3: Mental health challenges** | | |
| Subtheme 3a: Mental health challenges among HCPs | Parent | "There was a lot of trepidation by the nurses or a lot of fear in them, almost like overacting, kind of over doing it which made our time in the hospital post-transplant much more uncomfortable." |
| | Health care provider | "We were already limited [in] resources for our patient populations going into the pandemic, and then the added moral stress from the pandemic limiting those resources even more. For me as a physician, that was really hard because you… have a lot of years training for what you do well [and] to the best of your ability. But then when there's not a system or circumstances around you that allow that to happen, that sets the stage for physicians to feel that moral distress and ethical dilemmas around that. I would say that that's been the hardest part of the journey." |
| Subtheme 3b: Resource capacity issues for families and HCPs | Parent | "It was difficult because it… was like today you're in school and tomorrow you're not. None of [the children] had ever lived through online classes. You know, things were dropped … like it was just crazy. It wasn't just the fact that [child] couldn't focus… it was the fact that there was so much disorganization on top of the'non-focus'." |
| | Health care provider | "[Admission into the hospital was] incredibly tight and so I felt like there were a number of families that I basically coerced into going home and forced them to have [care] experiences at home because that was the only way that… we could provide the kind of care that was family-centered…. It was… really challenging and some of those conversations were terrible because… families had no options and that's not the way we practice, that's not what I do, and it was really, really frustrating and hard." |
| **General Theme 4: Recommendations to enhance service delivery** | | |
| Subtheme 4a:Redefine essential services | Parent | "On Friday and Saturday back in March, the message was, 'Yeah, the schools are going to be open' and then Sunday afternoon, it was, 'No, we are closing the schools'.… People need… more time to process this information and prepare, maybe make arrangements that would help. When it comes to daycares, of course, I do understand the [need to]… take special measures to basically keep everybody safe, but I think daycares should stay open… with strict protocol. I think that inability to go to work or kind of risking the job because you have to stay with your kid is a… huge stress and takes emotional toll." |

Table 4. Continued

| Theme | Participant group | Quote |
|---|---|---|
| | Health care provider | "I wish there was more clarity on…what is deemed essential. I think it was so unclear to families [whether or not] they were allowed to have respite…. At least fifty percent of them stopped having anyone come into their home so [parents] have 24 hours a day [sole responsibility for] their child with huge needs. They were in charge 24 hours a day which made them burn out." |
| Subtheme 4b: Building capacity in services | Parent | "[We need] more access to mental health resources, even particularly for children and resources for adults to use for children [such as] explaining to children the importance of social distancing and staying home, [and] why they can't have play dates or be at school right now. Yeah, explaining in children's terms what the virus is,… how to cope with their own feelings of, 'I miss my friends', and the extra stress and anxiety in the home." |
| | Child | "If I'm gonna be doing online school, I am gonna need some social activities." |
| | Health care provider | "We need to make sure that we always focus on the support system…. I think we need to make sure that we always include family support as part of our pandemic plan." |

wearing, reduced staff) created additional stress for parents who already were stressed and vulnerable in managing their child's health condition. Limited visitors and social distancing were perceived as particularly stressful for families of hospitalized children who were critically ill and/or at the end of life. Such changes drastically limited supporters at the bedside, imposed logistical challenge (e.g., childcare), and left children, parents, and other family members more isolated at key times of grief and loss. Infection control protocols were described as continually shifting, with insufficient time to make necessary accommodations. For instance, changes in visiting protocols demanded adjustment in employment and child care. Parents whose child was transferred between units or centres recounted varying protocols between and even within institutions (e.g., screening, visitation, quarantine).

Amidst many negative impacts on mental health, several children and parents described positive shifts. Some families in which a child had pre-existing mental health concerns noted that the child's mental health improved due to decreased demands in school and daily routines. Some children with underlying respiratory conditions found that isolation improved their physical health as they had less exposure to exacerbating illnesses. Families and HCPs identified shifts from in-person to virtual care as generally allowing increased flexibility.

### A lack of resources, with negative impacts on mental health

Insufficient availability of pandemic information/resources was highly concerning. Families identified extreme anxiety about virus risk to their child, with many unknowns about transmission and impact on the child's already-compromised health status. Fortunately, as more condition-specific information was released related to COVID-19, anxieties generally eased. Beyond common challenges across groups, unique issues within sub-populations were identified; for instance, parents of children with intellectual disabilities and autism reported difficulty finding materials to explain COVID-19 in a way that the child could easily understand.

### Organizational and policy influences shaping service delivery

#### *Mental health challenges among HCPs.*

The initial stages of the pandemic reflected uncertainty among HCPs about how public health requirements (e.g., masking, social distancing, quarantine) would alter paediatric practice. Infection control protocols were described to compromise the quality of care (e.g., reduced visitation, less timely access to resources) which impeded family-centred care. Witnessing these impacts imposed heightened HCP stress, including concern about sub-optimal patient care.

Workplace morale among HCPs reportedly shifted over extended pandemic duration. Although remote care was perceived as palatable by most HCPs, the shift to virtual care and disrupted staffing increased workload and created feelings of isolation and exhaustion. Ongoing changes in infection control protocols resulted in confusion, instances of relational conflict, and frustration. Some HCPs who sought to enforce infection control protocols identified verbal aggression directed at them.

#### *Resource gaps for vulnerable children, families, and HCPs.*

For most families, remote care was perceived as helpful and/or manageable, but was not optimal for children with acute illness or developmental or behavioral issues. For autistic children, virtual support (e.g., developmental therapies) was generally deemed less effective. Psychosocial supports that could have benefitted families (e.g., addressing anxiety and isolation) were unavailable or modified due to restrictions. These resource disruptions resulted in rapid pivots such as online education to parents of transplanted children, and virtual end-of-life rituals and bereavement support. Some integral community support (e.g., early intervention, counselling, respite care) was closed or substantially reduced, thus impeding wellness and stability.

Pandemic-related impacts on HCPs such as fatigue, malaise, anxiety and burn out, reportedly were communicated to senior administration. In varying degrees, HCPs felt that these issues were addressed, relative to other pressing pandemic-related demands on the care system. Negative psychosocial impacts of the pandemic on children and families were described to be somewhat buffered by the compassion of HCPs, and for HCPs, by the public's expressions of appreciation (early in the pandemic) and supportive professional/peer relationships within teams.

### Recommendations to enhance service delivery

#### *Redefine essential services.*

Families emphasized the importance of upholding essential services to address the particular needs of children with health vulnerabilities. Public health delineation of 'essential services' in the pandemic was perceived by families as too vague and limited relative to the nuances of clinical conditions. In some cases, a service that had not been determined 'essential' was substantially reduced, reportedly impeding family access to what was viewed as integrally needed (e.g., home care, early intervention, respite care). Such gaps reportedly resulted in deleterious impacts on individual and family functioning and mental health.

#### *Build service capacity.*

Mental health challenges of children and their families highlight the need for building capacity in service delivery during a pandemic (e.g., information access, tangible resources, coping support). Families and HCPs recommended tailored services addressing evolving needs as the pandemic persists and shifts. They stated that information about COVID-19 (or a future pandemic) and its impact on clinical populations need to be (i) delivered by experts, (ii) provided in an easy-to-understand format, (iii) tailored to the practical needs of children and families, (iv) offered comprehensively (e.g., clinical care guidance *and* psychosocial support), and (v) consistently communicated. Families suggested that mental health supports for children (e.g., psychoeducation, activities to promote well-being) should be more strongly integrated within online schooling to better address children's psychosocial needs, including transitioning to online school and coping with pandemic-related conditions. HCPs desired increased training in (i) digital platform use, (ii) ethical issues in care (e.g., confidentiality, privacy risks, access to care), and (iii) mental health resources for children and families specific to the pandemic context. Some of these shifts were thought to invite consideration in service delivery even beyond the pandemic (e.g., optimal use of technology in communication and care). Participants further recommended transparency within administrative structures, and reflection on the impact of pandemic-related program shifts on care experience and outcomes. Scrutiny of program and policy decisions on front-line practice and patient/family experience was viewed as critical in seeking to balance infection containment and child and family-centred care.

## DISCUSSION

While the COVID-19 pandemic has had far-reaching effects on all people, study results indicate particular and substantial mental health challenges for children with health vulnerabilities, and their families and HCPs. Isolation (16–18) and an increased burden of care (17) have been reported, as has strain on HCPs (19). Beyond these challenges, 'silver linings' reflect the resilience of the human condition in adversity, support offered to others, and gains made in technology use for patient care. The current study adds to this literature by examining the lived experiences of children with health vulnerabilities, their families, and HCPs. To our knowledge, this is the largest qualitative study to date exploring and integrating pandemic-related psychosocial and mental health outcomes of COVID-19 for these stakeholders.

These findings inform mental health supports for children, families, and HCPs. While the decision to predominantly provide online care and schooling was deemed necessary to protect the public, deleterious mental health outcomes have been imposed on children with health vulnerabilities and their families. In optimizing care, the nuanced needs of specific populations warrant prudent consideration by policy/program decision makers, reflective of specific care issues in the context of pandemic conditions. This study amplifies clinical groups who have experienced common and unique challenges, highlighting nuanced support needs among various populations. For instance, parents lacked materials to render COVID-19 understandable to their children with autism and intellectual disability. Multiple such challenges among clinical groups led to uncertainty, anxiety and suffering. Concerns have been raised by both parents and HCPs about the lack of condition-focused pandemic guidance. Accessible pandemic-relevant information and care guidelines targeting clinical groups are, thus, crucially needed.

For HCPs, study findings encourage heightened training and support to address pandemic-related paediatric practice. Capacity-building recommendations entail initiatives at an individual level (e.g., clinical and ethical guidelines), and organization/program level (e.g., education, mental wellness initiatives, feedback loops to address care/workplace challenges, IT innovation for remote care). Digital mental health support and educational resources introduced in the pandemic warrant evaluation to determine their effectiveness (20,21) and potential for sustained utility. Further, research is needed to guide pandemic planning, based on this and previous pandemics. Broader resource, program and system gaps amplified during the pandemic, highlight pressing priorities for improved cohesion of, and access to, health and social care and educational services, with particular attention to the unique needs of children with health vulnerabilities. Guidance to families, HCPs, teachers, service providers, and other relevant stakeholders is recommended in nurturing integrated services during and beyond the pandemic.

Overall, study findings highlight the importance of proactive service delivery planning for this and potentially future pandemics. Supportive networks for HCPs (e.g., supervision, peer support, debriefing opportunities) are demonstrated to help manage pandemic-related stress among HCPs (22). Buffering strategies include transparent and responsive communication, intentional support, wellness programming, and proactive care policies/guidelines. Findings highlight the need to offer families targeted education, child and family wellness initiatives, financial resources, and transparent and responsive protocols specific to pandemic conditions.

In considering the limitations of this study, caution is recommended regarding widespread applicability of findings because data were collected in only two Canadian provinces and among a limited number of clinical populations. It is further recognized that individual and family experiences of the pandemic shifted over its duration and restriction intensity, thus warranting long-term study over pandemic conditions, intensity, and duration. Future research must also address means of post-pandemic recovery.

Notwithstanding these study limitations, this study offers an important exploratory understanding about the impacts of the pandemic on the mental health of children with health vulnerabilities and their families as well as HCPs. These findings amplify the need for sufficiency in system capacity, including proactive strategies and supports in this and the potential event of a future pandemic.

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