CARING FOR CHILDREN AND YOUTH WITH COMPLEX CARE NEEDS DURING THE COVID-19 PANDEMIC: A NEW BRUNSWICK PERSPECTIVE

Lillian MacNeill, A. Luke MacNeill, Shelley Doucet, and Alison Luke

Abstract

The COVID-19 pandemic has caused disruptions to health and social care across Canada. These disruptions may have a disproportionate impact on people caring for children and youth with complex care needs. The purpose of this qualitative study was to explore the experiences of caregivers and care providers of children and youth with complex care needs in New Brunswick during the COVID-19 pandemic. Forty-five caregivers and seven care providers were recruited for the study. They completed an online survey that included open-ended questions about their experiences caring for children and youth with complex care needs during the pandemic. The most common themes identified in the data were: (1) a loss of support for caregivers and their children/youth; (2) a negative impact on the mental health of caregivers and their children/youth; and (3) struggles to balance safety and quality of care. These results provide stakeholders involved in the care of children and youth requiring complex care with information and recommendations to improve the delivery of care during periods of strain on the healthcare system.

Résumé

La pandémie de COVID-19 a causé des perturbations dans les services de santé et sociaux partout au Canada. De telles perturbations peuvent avoir un impact disproportionné sur les personnes qui s’occupent d’enfants et de jeunes ayant des besoins complexes en matière de soins. Le but de cette étude qualitative était d’explorer les expériences des soignants et des fournisseurs de soins d’enfants et de jeunes ayant des besoins de soins complexes au Nouveau-Brunswick pendant la pandémie de COVID-19. Quarante-cinq soignants et sept prestataires de soins ont été recrutés pour l’étude. Ils ont répondu à un sondage en ligne qui comprenait des questions ouvertes sur leurs expériences de prise en charge d’enfants et de jeunes ayant des besoins de soins complexes pendant la pandémie. Les thèmes les plus courants identifiés dans les données étaient les suivants : (1) une perte de soutien pour les soignants et leurs enfants/jeunes ; (2) un impact négatif sur la santé mentale des soignants et de leurs enfants/jeunes ; et (3) des défis dans l’équilibre de la sécurité et de la qualité des soins. Ces résultats fournissent aux intervenants impliqués dans la prise en charge des enfants et des jeunes ayant des besoins de soins complexes des informations et des recommandations pour améliorer la prestation des soins en période de pression sur le système de santé.

Background

The COVID-19 pandemic has prompted changes to the delivery of health and social care across Canada. These measures have been necessary to protect the general public and the health system at large, but they have created gaps and challenges in many areas of health and social services. For example, during lockdowns to stem the spread of COVID-19, access to health services was reduced and appointments were often conducted virtually through telehealth services (D'Alessandro et al. 2020; Wong et al. 2021). In a similar manner, most educational and community services were curtailed or shifted to virtual delivery models (Lee et al. 2021; Silverman et al. 2020). Even after lockdowns ended, many of these precautions were maintained to help prevent the spread of COVID-19. Given the breadth of this response and the duration of the pandemic, most of the public has been affected by these changes to some degree.

The impact of the COVID-19 pandemic on health and social care may be particularly severe for those individuals caring for children and youth with complex care needs. Broadly speaking, complex care needs (CCN) are multidimensional care needs that involve some combination of medical, social, and behavioural factors (Brenner et al. 2018; Grant et al. 2011). Children and youth with CCN are a small percentage of the pediatric population, but they are high users of health, social, and educational care systems (Bhawra et al. 2016; Breneol et al. 2017; Brenner et al. 2018; Cohen et al. 2012). As one might expect, managing the care of these individuals can be challenging under normal circumstances (Charlton et al. 2017). Disruptions to health and social care caused by the COVID-19 pandemic may have exacerbated the difficulties that caregivers and care providers typically experience in providing care to this population.

To date, the care of children and youth with CCN has received little direct attention in the literature surrounding the COVID-19 pandemic. However, recent studies have shown that the pandemic has increased stress and care challenges in caregivers of pediatric patients more generally (Arim et al. 2020; Asbury et al. 2020; Cacioppo et al. 2021; Darlington et al. 2020; Ergenekon et al. 2020; Prime et al. 2020), and in pediatric care providers who work within the health system (Nicholas et al. 2020). For example, research indicates that the pandemic has created difficulties for caregivers of children and youth with autism (Friesen et al. 2022; Lee et al. 2021), Type 1 diabetes (Alessi et al. 2021; Ismail et al. 2022), and eating disorders (Maunder and McNicholas 2021), including disrupted care services and declines in mental health. Although none of these studies addressed the topic of CCN explicitly, children and youth with these types of conditions often have more complex health and social care needs (Charlton et al. 2017). Given the inherent challenges associated with caring for children and youth with CCN, it is important to determine how the COVID-19 pandemic has affected caregivers and care providers of this population.

The purpose of the current study was to explore the experiences of caregivers and care providers of children and youth with CCN during the COVID-19 pandemic in New Brunswick. New Brunswick offers a unique setting for a study on the impact of the pandemic, as it has a relatively large rural population and a handful of small urban centres. These demographic characteristics were impediments to the delivery of health and social services prior to the onset of the pandemic (Foroughi et al. 2020; McGeorge and Bateman 2017; Miedema et al. 2009), and disruptions resulting from the pandemic have likely aggravated these issues to a certain extent. The results of this study were expected to provide insight into the experiences of people caring for children and youth with CCN in New Brunswick during the pandemic. They were also expected to offer direction on how the province of New Brunswick—and regions facing similar demographic issues—might improve services for these caregivers and care providers during a large-scale health crisis.

Methods

Design

This study followed a cross-sectional qualitative descriptive design. Qualitative description is often used when researchers seek to understand a phenomenon but wish to interpret the findings without moving too far from the surface data (Sandelowski 2010). Qualitative description is particularly useful when researchers seek to learn from participants' descriptions and use this knowledge to influence interventions and promote policy change (Bradshaw et al. 2017; Sullivan-Bolyai et al. 2005; Kim et al. 2017).

Participants

We recruited caregivers and care providers responsible for the health and social care of children and/or youth with CCN in New Brunswick. For the purpose of this study, a caregiver is defined as a child's legal guardian or another family member who is primarily responsible for meeting their care needs. A care provider is defined as a health professional, allied health professional, or other care worker responsible for coordinating or delivering health or social care to children/youth with CCN. Participants were recruited online through social media channels (e.g., Facebook) as well as targeted emails and newsletters from organizations providing support to families of children and youth with CCN (e.g., Ability New Brunswick). Recruitment for the survey took place over a six-month period (May 2020 to September 2020). All participants were required to be nineteen years of age or older, residents of New Brunswick, and capable of communicating in English. Individuals who participated in this study were entered into a draw to win one of two $100 Amazon gift cards.

Procedure

This study was approved by the University of New Brunswick's Research Ethics Board (REB # 015-2020). Participants were directed via a weblink to the Qualtrics online survey platform, which hosted the study materials. Participants began by completing an informed consent form and a demographic questionnaire. Next, they were asked to answer several qualitative, open-ended questions about their experiences caring for children and youth with CCN during the pandemic. These questions broadly addressed topics such as changes in care, challenges experienced, and service needs (e.g., "What changes, if any, have been made to your child/youth's healthcare services?"). Questions were presented in a written questionnaire format (i.e., no in-person or virtual interviews were performed). Questionnaires were used for data collection given that other research methods were restricted and/or impractical in the early stages of the pandemic when the study was conducted.

Once the data collection was complete, the information was entered into NVivo (Version 12) for analysis. The information was examined using thematic analysis, which is often used to search for and identify common themes across a data set (Braun & Clarke 2006). This study was guided by Braun and Clarke's six phases of thematic analysis: (1) become familiar with the data; (2) generate initial codes; (3) search for themes; (4) review themes; (5) define and name themes; and (6) report findings. To ensure that analysis of the transcripts was conducted with the appropriate rigour, two co-investigators each coded 20 per cent of the transcripts to generate preliminary codes and working definitions, which then guided the subsequent analysis.

Results

Participant Characteristics

Caregivers

The caregiver sample consisted of forty-five individuals aged twenty-eight to sixty-two years (*M* = 41.75 years; *SD* = 7.95). Most participants identified as female (*N* = 41). The sample included twenty caregivers from urban areas, thirteen caregivers from suburban areas, and twelve caregivers from rural areas of New Brunswick. Most of these individuals lived in Health Zone 2 (Saint John area; *N* = 35), and the remaining caregivers lived in Health Zone 1 (Moncton area; *N* = 7), Health Zone 3 (Fredericton area; *N* = 2), and Health Zone 6 (Bathurst area; *N* = 1). Twenty-six participants reported being employed, and the rest of the sample consisted of nine homemakers, three students, five people receiving social assistance, and two individuals who were otherwise unemployed. Notably, eighteen caregivers (40 per cent) reported loss of employment within their household due to COVID-19 restrictions.

In terms of caregiver roles, almost all participants indicated that they were the mother of a child or youth with CCN (*N* = 40). Most caregivers (*N* = 38) reported having one child or youth with CCN in their household, while the rest of the sample reported either two (*N* = 5) or three (*N* = 2) children or youth with CCN. In addition, nineteen caregivers reported that they were the primary caregiver for someone other than their dependent(s) with CCN. The ages of their children or youth with CCN ranged from less than one year to twenty-one years (*M* = 11.46 years, *SD* = 4.63), and just over half were reported to be male. Children and youth had a wide variety of diagnoses, although the most common ones reported by caregivers were autism spectrum disorder (*N* = 23), attention deficit hyperactivity disorder (*N* = 11), and an anxiety disorder (*N* = 7).

Care Providers

The care provider sample was made up of seven individuals aged twenty-seven to thirty-eight years (*M* = 31.5 years, *SD* = 4.0). All care providers identified as female. The sample consisted of four care providers practising in urban areas and three in rural areas of New Brunswick. Care providers had been practising for an average of 6.1 years, and none of them reported a loss of employment due to COVID-19 restrictions. Six of the seven care providers shared their professional background: youth care worker (*N* = 3), certified behaviour analyst (*N* = 1), human service worker (*N* = 1), and physiotherapist (*N* = 1).

Survey Results

The most common themes identified in the data were: (1) a loss of support for caregivers and their children/youth; (2) a negative impact on the mental health of caregivers and their children/youth; and (3) struggles to balance safety and quality of care.

Loss of Support for Caregivers and Their Children/Youth

Caregivers reported a loss of support for themselves and their children/youth with CCN during the COVID-19 pandemic. This loss of support included several subthemes, the first of which was the loss of personal support. Support within this subtheme referred to the informal support that caregivers received from their extended family, as well as formal childcare and in-home support (e.g., respite care). For example, one caregiver disclosed: “Our home is closed to visitors, so we are very limited socially and in terms of support. Our family and friends can only offer limited verbal support from a distance.” Other caregivers said: “We lost all physical social supports until the bubble[1] was allowed” and “There isn’t a network for me anymore.” Caregivers emphasized how this loss of support increased their caregiver burden. One caregiver declared: “Our support worker wasn’t able to help, respite care wasn’t an option, there is never a break”; while another reported: “I wish I had more physical support. A break.”

Caregivers also described a loss of health care support for their children/youth with CCN. Many caregivers reported either a reduction in services or a complete loss thereof (i.e., cancellation of health care appointments). One caregiver stated: “Any support such as mental health counsellor appointments had to be done over Zoom [video conferencing platform].” Other caregivers said: “He had appointments with his doctor cancelled as well as his mental health counselling stopped” and “My son receives in-home ABA [applied behavioural analysis] therapy twenty hours per week; these in-person services were unavailable.” Care providers recognized these difficulties. For instance, one care provider noted that her clients experienced “increased care/therapy needs due to decreased face-to-face services.” Care providers also acknowledged that some caregivers had to take a more direct role in the health care of their child/youth. One care provider reported that caregivers were “delivering therapy usually done by professionals, [like] speech [therapy].” Several caregivers expressed a desire for continued support from care providers during lockdowns. One caregiver said: “I feel that all physiotherapy should have stayed available. Having a long break in therapy can lead to regression”; while another declared: “[They] would benefit from continued routine and support from [their] speech therapist.”

Another major challenge for caregivers was the loss of school or educational support. Caregivers reported that their children and youth had difficulty adapting to home-schooling and a virtual learning environment. For example, one caregiver stated that their child “has had a hard time dealing with school by way of telephone and email”; while another reported: “[Child] was unable to do any online learning at school, which he missed.” Loss of school and educational support placed a major burden on caregivers. For example, one caregiver acknowledged this difficulty by stating:

> The biggest challenge is wearing multiple hats at the same time. As a caregiver who moved to working from home in March, I was expected to continue working, teaching, and supporting a child with a learning plan, who in a given week would have the support of about five specialists in the school system.

Along the same lines, another caregiver noted:

> The biggest challenge was having the schools/daycares close, which is completely understandable, but then not being able to have anyone in to watch him while I tried to work from home. My son needs constant help, constant supervision, especially because he is a flight risk.

Caregivers wanted to have more educational support during the pandemic, although they tended to be vague or nonspecific on what form of support would be best. For example, one caregiver said that they would benefit from “more resources for home-schooling”; and another stated: “Finding help for myself and for my daughter [who has] learning disabilities would make it a lot easier.”

The loss of support across so many domains seemed to have a disruptive influence on the routines of caregivers and their families. For example, one caregiver stated: "The lockdown was very difficult because it turned [the child's] routines upside down." Another shared similar concerns: "Getting them to keep any sort of routine has been incredibly hard." The closure of daycares and schools during lockdowns seemed to be the largest contributor to this loss of daily structure.

A Negative Impact on the Mental Health of Caregivers and Their Children/Youth

In their reports, caregivers indicated that the loss of support described in the previous section had a negative impact on their mental health. One caregiver stated: "I was asked to work from home. I then had to work forty hours from home with a child who has special needs and taking a meltdown almost every hour. I have fallen behind in work, and my stress level is at an all-time high." Another said: "I feel stress regularly but it's a part of our lives, and we always manage…. With COVID, it has been very difficult, and truly the most challenging time in my life." Other caregivers echoed this sentiment with respect to their children: "[The biggest challenge is] dealing with their anxieties and fears for this pandemic and just generally"; "My daughter is bored and depressed. It's been harder than normal"; "During the pandemic … we dealt with self-injurious behaviours from both of our children." Several caregivers indicated that increased access to mental health services is needed for families caring for children and youth with CCN. Specifically, they expressed a desire for "more support mentally for us [caregivers]" and "free therapy for those who need it."

Reinforcing caregiver reports, care providers perceived that families were experiencing increased mental health symptoms such as stress and anxiety during the pandemic. For example, one care provider reported "increased mental and emotional stress/burden on parents," whereas another acknowledged that "youth are more prone to bad mental health days." Some care providers expressed frustration at the lack of mental health support for these families: "Therapy and face-to-face counselling could have kept going but with proper social distancing and glass." Others indicated that increasing mental health support would be helpful: "I think counselling programs specifically for parents with children who have complex needs would be extremely beneficial especially during this time where parents might be with their child 24/7 and not be able to see any other adults."

Struggles to Balance Safety and Quality of Care

Like caregivers, care providers experienced challenges caring for children and youth with CCN during the pandemic. Care providers reported that their biggest challenge was balancing safety and quality of care. One care provider found it challenging to "keep everyone healthy while still providing a quality service," and another expressed difficulty "ensuring ongoing access to services while balancing the health/safety risk of children/families." Care providers were also mindful of the risks associated with limiting care: "I have now witnessed multiple children in crisis who are self-harming, hurting others, and need immediate intervention, but youth care workers don't want to get too close because of COVID-19 risk." Several caregivers found it difficult to manage the increased safety protocols that this balance required. For example, one caregiver explained: "When [the youth] went to the [hospital] for skin treatment three days a week, they would try to make him go on his own and I would have to explain each time why [they] couldn't." Another specified: "[I] was not able to stay in hospital with her, it was her first time alone and for two weeks." When considered in conjunction with the first two themes, these latter results suggest an interesting dichotomy: many caregivers were forced to play a greater role in the day-to-day care of their children or youth, while also having less direct involvement in their formal health care.

Discussion

The results of this study suggest that the COVID-19 pandemic has had a negative impact on caregivers and care providers of children and youth with CCN in New Brunswick. As one might expect, lockdowns, social distancing, and related disruptions to health and social care caused a loss of support for caregivers and their children/youth with CCN. Caregivers reported feeling overwhelmed trying to meet the demands of their children/youth's special health and educational needs without the assistance of their previous supports. Their struggles seemed to be especially severe when they continued to be employed and at the same time had to meet the overall needs of their families. In these situations, caregivers were forced to maintain their normal pre-pandemic roles while adopting additional support roles for their children/youth with CCN. These findings are consistent with recent studies that have also identified the loss of resources and support for caregivers as a major challenge during the pandemic (Arim et al. 2020; Asbury et al. 2021; Friesen et al. 2022; Griffith 2022; Lee et al. 2021; Shorey et al. 2020; Willner et al. 2020).

The reported loss of support seemed to contribute to a decline in the mental health of caregivers and their children/youth. Caregivers tended to feel overwhelmed by their expanded caregiving roles, and their mental health struggles made it more challenging for them to care for their families. In addition, many caregivers reported concerns about their child's/youth's mental health. The majority of these children/youth had cognitive, behavioural, or emotional conditions that are associated with mental health issues (e.g., autism spectrum disorder or attention deficit hyperactivity disorder). It is possible that a loss of support, in conjunction with lockdowns and social distancing, exacerbated any pre-existing mental health issues that these children/youth may have been experiencing. These findings echo recent studies in which parents reported mental health declines within their families (Asbury et al. 2021; Chen et al. 2020; Dhiman et al. 2020; Prime et al. 2020; Willner et al. 2020) and concerns about the mental health of their children (Arim et al. 2020; Asbury et al. 2020; Prime et al. 2020) during the pandemic.

Care providers reported their own unique challenges during the COVID-19 pandemic. The main theme identified in their reports was the pressure to balance safety and quality of care. Care providers were sympathetic to caregivers of children/youth with CCN and genuinely seemed to want to continue providing high quality care. They recognized that withdrawing or limiting care could have serious repercussions for their patients or clients. However, they were also mindful of the risks associated with their profession, particularly in terms of acquiring and spreading the virus to vulnerable populations. These findings echo concerns expressed during a recent roundtable discussion with Canadian pediatric clinicians (Nicholas et al. 2020). These clinicians discussed the importance of balancing the risks of COVID-19 exposure with the risks of withdrawing services for the pediatric population. They noted that care must remain available to children and their families, albeit with shifted expectations and delivery models for safety purposes.

Participants in this study offered several recommendations for addressing pandemic-related issues. Both caregivers and care providers wanted to see improvements in the availability of support services to help meet the health and educational needs of children and youth with CCN and their families. Other suggestions included increasing the availability of educational resources when remote learning is mandated or necessary and maintaining the continuity of services delivered by allied health professionals (e.g., speech language therapy and physical therapy) to avoid declines in progress. Unfortunately, participants offered few suggestions on how to make the balance between safety and quality of care more manageable. Although results indicated that caregivers experienced difficulties adjusting to virtual/telehealth services and restrictions to in-person health appointments, these service adjustments were perhaps the most effective way for care providers to find a reasonable balance between safety and quality of care.

Limitations

There were some important limitations to this study. Most of the participants were Anglophones from the southern region of New Brunswick, which can likely be attributed to the specific recruitment channels that were used for the study and the fact that the survey was only offered in English. It is unclear whether the results of this study reflect the experiences of other caregivers and care providers in New Brunswick, such as Francophones or those who live in northern areas of the province. Another limitation is that the study sample only contained seven care providers, all of whom were female and most of whom were working in the social sector. Although the results were fairly consistent among these participants, it is unclear how well the findings reflect the experiences and views of other care providers.

Conclusion

The results of this study provide insight into how caregivers and care providers of children and youth with CCN in New Brunswick have responded to the COVID-19 pandemic. In addition to highlighting some of the challenges that these people have faced, this study also outlines some concrete steps that can be taken to address issues stemming from the pandemic. Implementing these steps will not only help caregivers and care providers during the current pandemic, but it will also facilitate a better state of preparedness for future health emergencies in the province.

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Lillian MacNeill is a research associate with the Centre for Research in Integrated Care in the Department of Nursing and Health Sciences at the University of New Brunswick.

A. Luke MacNeill is a postdoctoral fellow with the Centre for Research in Integrated Care in the Department of Nursing and Health Sciences at the University of New Brunswick.

Shelley Doucet is a professor in the Department of Nursing and Health Sciences and the director of the Centre for Research in Integrated Care at the University of New Brunswick. She is the Jarislowsky Chair in Interprofessional Patient-Centred Care.

Alison Luke is a research associate at the Centre for Research in Integrated Care in the Department of Nursing and Health Sciences at the University of New Brunswick.

Note

[1] Referring to the travel bubble between the Atlantic Canadian provinces.

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