



# Respite care: qualitative arts-based findings on the perspectives and experiences of families of children and youth with special healthcare needs residing in Manitoba, Canada

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# BMJ Open Respite care: qualitative arts-based findings on the perspectives and experiences of families of children and youth with special healthcare needs residing in Manitoba, Canada

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## ABSTRACT

**Objectives** Respite for families of children and youth with special healthcare needs (CYSHCN) is essential for sustaining a family care environment. Lacking is an understanding of families' respite experiences who reside in Canada. We sought to understand experiences of the use of respite services by families with CYSHCN with the aim to help improve respite services. This paper reports on the qualitative arts-based findings.

**Design** Qualitative methods including open-ended interviews combined with the arts-based methods of ecomaps and the photovoice process were used. Analysis involved delineating units of meaning from the data, clustering units of meaning to form thematic statements and extracting themes.

### Setting

Manitoba, a western Canadian province.

**Participants** Thirty-two families (including 38 parents and 13 siblings) of CYSHCN.

**Results** We identified six themes surrounding challenges experienced by families' in their journeys accessing, acquiring and navigating the respite care system, and sustainment of respite care for their families, leading to familial burn-out and breakdown, financial stress, unemployment and unaddressed mental health struggles. Families provided multipronged recommendations to address these challenges.

**Conclusions** Through the lens of Canadian families of children with a range of complex care needs, the qualitative arts-based portion of the study underscores the challenges with accessing, navigating and sustaining respite care, which has implications for CYSHCN, their clinicians and the potential for long-term costs for government and society. This study identifies the state of the current Manitoba respite care system as an issue, presenting actionable recommendations from families that can assist policymakers and clinicians in advocating for and implementing a collaborative, responsive, family-centred system of respite care.

While generalization of findings to populations of families of CYSHCN in other jurisdictions in Canada and beyond is not the goal of qualitative research, these findings nonetheless can be used by

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ There are few Canadian studies within the past 10 years exploring the respite experiences of families with children and youth with special healthcare needs (CYSHCN) to understand current challenges with accessing respite services, along with their solutions to address these challenges.
- ⇒ Inclusion of questions relating to participating family characteristics, primary conditions of CYSHCN of participating families and self-reported respite hours received provides a comprehensive picture of families' situations.
- ⇒ We used multiple research methods, including open-ended interviews (individual and family), photo voice and ecomaps to generate our significant findings.
- ⇒ Limitations of sample include few newcomers and fathers.

others in understanding the experiences of the use of respite services by families with CYSHCN.

## INTRODUCTION

The Canadian Institute for Health Information states that children and youth with medical complexity, including a range of single or multiple conditions, neurological impairment or neurological impairment with other condition(s), share four characteristics: complex chronic conditions, functional limitations, high healthcare utilisation and caregiving needs.<sup>1</sup> The unique needs of these Canadians requires extensive physical, financial and social resources to participate in daily life,<sup>2-4</sup> and achieve optimal outcomes.<sup>5</sup> Between 2010 and 2016, there were 97561 Canadian children and youth (aged 0–24 years) with medical complexity, an age-adjusted rate across provinces of 948 per 100 000<sup>1</sup> sparking increased demand for



extensive medical therapies and supports.<sup>5,6</sup> Advances in medical care, and shifts in public policy in Canada have led to increasing numbers of children and youth with medical complexity to be cared for within Canadians' homes (vs hospitals or institutions).<sup>7</sup> However, Canadian healthcare systems have yet to address the rising demand for and coordination of care of children and youth with special healthcare needs (CYSHCN), tasking families with the brunt of caregiving duties.<sup>6,8</sup> Caregiving for these children and youth varies based on needs and conditions, including behavioural monitoring, mobility, ventilator or feeding support, medical therapy, and or assistive technology dependence, sometimes resulting in the need for 24-hour care.

While there is no agreed on definition, here, we use the term CYSHCN which includes infants, children and youth who have one or more chronic physical, developmental, behavioural or emotional conditions, and require special health and support services. As primary caregivers of CYSHCN, parents struggle to maintain a balance between social and work life, personal well-being and this unique context of parenting.<sup>3,9</sup> Moreover, having CYSHCN greatly impacts the family dynamic especially for siblings who may assume caretaker roles, feel protective over their sibling with complex care needs or experience mental health challenges.<sup>10-12</sup> Although family members of CYSHCN may share deep connections, negative outcomes such as emotional exhaustion are evident.<sup>10,13</sup> Respite care (short-term breaks), either in-home or out-of-home can benefit parents, the CYSHCN and siblings<sup>4,14,15</sup> and sustain family care environments, reducing parental stress, anxiety and depression,<sup>16</sup> while addressing needs of CYSHCN.<sup>15</sup> Respite care services vary across Canada both interprovincially and intraprovincially. Although respite may be for a crisis intervention, it is ideally a component of a supportive network provided for caregivers but may also be for the CYSHCN.<sup>15</sup> In Manitoba, Canada, for example, the provincially administered Children's disABILITY Services programme provides respite to parents who are caring for a child under age 18 who have a diagnosis of specific conditions, for example, intellectual disability, developmental delay, autism spectrum disorder or lifelong physical disability. Depending on eligibility, assessed needs and available resources, respite may be provided in or outside the child's home by a worker, or in-home by a nurse for complex medical needs. Some funding for certain supplies, equipment or transportation may also be available.<sup>17</sup>

Although respite care offers many benefits, Nuri *et al* identify five key themes impacting respite access: availability, accessibility, affordability, acceptability and awareness, with barriers including staff shortages, long wait times, lack of service coordination, social stigma and limited knowledge concerning service eligibility.<sup>18</sup> Parents have also reported a lack of information and knowledge regarding available respite and support services,<sup>19</sup> and needing to 'jump through hoops' for respite service qualification.<sup>20,21</sup>

Reports of unmet respite needs from the literature, families and service providers have long been seen,<sup>22,23</sup> and past research<sup>18,22,24</sup> has framed respite access as an undeniable problem. While the networks for change exist,<sup>25</sup> there has been minimal social or government action towards change. Why has lack of adequate access and receipt of respite care not been formally named as an issue—a human rights violation,<sup>26</sup> adopted and championed?<sup>27</sup> Perhaps, because respite care and its numerous systemic shortcomings have been deemed a non-issue, one that can be neglected without substantial consequences for policy-makers and the public.

To this end, previous research primarily with American parents or siblings of CYSHCN highlights recommendations for addressing barriers to respite services including improved communications between service providers and families,<sup>28,29</sup> enhanced coordination of services,<sup>28,29</sup> family-focused approaches,<sup>30,31</sup> family empowerment,<sup>30,31</sup> increased education about disabilities<sup>29</sup> and support with system navigation.<sup>30</sup>

However, as noted by the Canadian Healthcare Association, there is a need to pursue Canadian research on respite care that will result in improvement in the services themselves.<sup>15</sup> Furthermore, there are few Canadian studies within the past 10 years exploring experiences with respite from the perspective of families (both parents and siblings) of CYSHCN to understand familial challenges with respite, together with their recommendations for addressing these challenges. This paper addresses these gaps, using multiple methods, reporting on the qualitative arts-based findings specific to families residing in Manitoba, Canada.

## METHODS

The findings reported in this paper are part of a mixed-methods study gathering evidence to inform respite care that is responsive and integrative for families of CYSHCN in Manitoba. Not reported in this paper are a quantitative component using administrative data<sup>32</sup> and findings from interviews with respite services administrators and providers.

### Study design and participant selection

Qualitative, arts-based methodologies were employed to elucidate the respite care experiences of families of CYSHCN along with proposed recommendations to enhance respite care. These methodologies provided a creative way for study participants to share their stories and illuminate the human dimensions of health and illness.<sup>33,34</sup>

Manitoba (MB), Canada families (mothers, fathers and siblings) of CYSHCN who were receiving specialised healthcare services were recruited using purposive and snowball sampling from 10 local healthcare centres, family networks and community agencies that provide specialised services/supports for this population, through posters, invitation letters sent to families

and via social media until theoretical saturation was achieved.<sup>35 36</sup> Study personnel then contacted interested families who consented, leaving the choice to families to decide which member(s), for example, mothers, fathers and/or siblings would participate. The study was further explained and scheduled for in-person or virtual interviews.

### Data collection

Multiple data collection methods were used to examine families' perspectives, providing complementary insights that may otherwise be difficult to access if using a single method.<sup>37 38</sup> One author (AK) with direction from a second author (RLW) collected the data. Both researchers (female) were trained in qualitative interviewing and arts-based data collection methods. Data collection took place between November 2019 and April 2022. Shortly after the start of this study, the COVID-19 pandemic emerged resulting in most data collection taking place virtually.

Family caregiver(s) (eg, mothers, fathers, siblings) completed a demographic form, and then took part in an open-ended interview using various strategies to facilitate discussion<sup>39 40</sup> to understand their experiences of using respite services and their recommendations for future respite care. Although taking place during the pandemic, families were asked to focus on their overall respite care experiences. An additional question was added to the interview about how the pandemic had impacted their overall respite experiences. Interviews took place either at local coffee shops or virtually, lasted between 90 and 120 min and were digitally recorded and transcribed verbatim. When multiple caregivers were present in the family, they were interviewed separately to afford privacy and adequate time (see online supplemental appendix 1: Interview Guides). Each family member was given an opportunity to draw an ecomap at the beginning of their first open-ended interview, a graphical portrayal of social relationships or networks, key events, places or issues.<sup>41</sup> After the first interview, families were given instructions about the photovoice process<sup>33 42</sup> previously used in research with children<sup>33</sup> and adults.<sup>43</sup> After completing the photovoice activity, families participated in a digitally recorded family-group interview (online supplemental appendix 1: Interview Guides—see Photovoice Interview Guide), capturing interactional data or shared realities<sup>44</sup> and contextualising photovoice stories. Using probes and the SHOWeD<sup>45</sup> interview method, families were guided through each photo by asking them the why, what and how, of their photos in relation to respite care, thus allowing opportunity for participant feedback on their interviews. All participants consented to have their photos or ecomaps used, and families/family members chose which photos to submit. Field notes were recorded following each interview. Identifying information was removed to protect confidentiality.

### Data analysis

In keeping with the qualitative paradigm, data analysis occurred concurrently with data collection. Informing the data analysis process was all the data emerging from the interviews and field notes (textual data) and photographs and ecomaps (graphical data). Participant quotes and field note data were entered manually into a Microsoft Word document and organised by themes. The inductive approach of thematic analysis which involves identifying recurrent themes across participants was applied.<sup>36 46 47</sup> First, the interview transcripts were read and reread to get a sense of the data and overall meaning. This was followed by searching and delineating units of meaning from the textual data. Units of meaning with similar patterns and relationships of meaning were then grouped together to create themes. These themes were then collated and discussed (RLW, CI and AK). Any discrepancies or uncertainty of themes were resolved via discussion among all three authors until consensus was achieved. Attention was given to exploring similarities and differences between participants throughout data analysis. Themes were refined after comparing data from the first set of interviews with the second set of interviews. During the second interviews, preliminary analyses were discussed with participants which helped to uncover and lend support for the identified themes. The photos and ecomaps served as visual representations of the text-based findings and informed the themes emerging from the data. By relating the visual data to the corresponding transcripts, we gained a greater understanding of families' experiences. All data were reviewed repeatedly for significant statements to fully understand participants' lived worlds and meanings of their experiences through themes (RLW, CI and AK).<sup>46</sup> To enhance the methodological rigour of the study, measures were applied including prolonged engagement with participants and data, careful line-by-line analysis of the interview transcripts, and detailed memo writing<sup>39 46</sup> was in place.

The Family Advisory Committee (FAC), made up of six members representing six different participating families, were presented with findings and reviewed the major themes on an ongoing basis. After meetings, notes were made, and assumptions checked to ensure no researcher bias.

Participant demographics were calculated using basic descriptive statistics, including means, frequencies and ranges using SAS V.9.4. (RLW and CI)<sup>48</sup>

### Patient and public involvement

Patients, researchers, clinicians and decision-makers along with our FAC, composed of members of participating families of CYSHCN were part of the research team. The FAC was formed and met regularly to advise and work with the research team members, knowledge users and collaborators throughout the study to ensure findings were translated in a meaningful way.

## FINDINGS

### Participants

Of those families approached none refused to participate, resulting in 32 families taking part in the study. Of the 32 families, participant representation was as follows: 1 parent only,<sup>19</sup> 2 parents only,<sup>3</sup> 1 parent and 1 sibling,<sup>4</sup> 1 parent and 2 siblings,<sup>3</sup> 2 parents and 1 sibling.<sup>3</sup> There were no siblings who were included without parents also taking part. Six of the families did only the first interview as they could not complete all phases due to time, etc, however their data were used to inform this paper. See [table 1](#) for participant characteristics. Although invitations were sent to families, primarily mothers responded. The pandemic did not seem to affect recruitment and may have made participating simpler as no travel was required. Further, while the intent was to include CYSHCN in the interviews, given less than five participated, their responses are not included to protect confidentiality.

Among CYSHCN in participating families (n=34), more than half (20; 58.82%) had a primary diagnosis of Developmental/cognitive disorder, while genetic/chromosomal abnormality and neuromuscular or seizure/pPhysical disorder diagnoses categories each represented 20.59% of these children. Additionally, 58.83% had between one and four co-occurring conditions. Participating families reported receiving from 0 up to 35 hours of respite per week, resulting in an average (mean) of 8 hours of respite care per week over the past 12 months.

### Themes

#### A: challenges

Multiple methods (ecomaps, family interviews and photovoice activity) builds on the story of families' challenges with respite care. Six themes emerged from these methods encompassing families' challenges with accessing, acquiring and navigating the respite care system, sustaining appropriate care for their CYSHCN, and COVID-19 pandemic-accentuated challenges.

#### 'You don't know what you don't know'

This theme refers to the lack of available information about respite services resulting in families' lack of knowledge about respite and service options and how this in turn precluded them from knowing potential questions to ask that might lead to their child receiving respite care.

For example, many parents expressed not knowing what respite was, what to ask for, how it could benefit their family or where to apply for respite services. *You are going in there (respite system) flying blind and you don't know what you are entitled to. If you don't know, you don't know. That is the problem when you don't know what is covered by respite* [Father 07]. Other families did not learn about respite services entitlements until their child was older as shared by a mother.

You need someone that can intervene for you because you don't know what you don't know and that's the biggest problem. We found out years later that we didn't have to pay for certain things that we had

to get for 'B'. Just there was no way of knowing this. [Mother 04]

Further, inconsistencies and *no real rhyme or reason to if people get accepted* [Mother 28] were noted regarding eligibility, while the hours of respite care families received was explained as being *all over the map* [Mother 01]. Those who were strong advocates, comfortable navigating the system were often able to secure services for their CYSHCN, potentially leaving families lacking these skills without adequate respite.

#### Always waiting

The theme, always waiting, refers to the long journey of wait times reported by families when attempting to access each stage of the respite system. The excerpt below describes one families' arduous experience of obtaining a respite-eligible diagnosis and waiting for a case worker.

To get respite support, what do you have to do? You as a parent have to identify that there are issues, you have to go to the doctor, you have to wait for a referral. Wait lists for [Treatment Centre] are easily a year right now, if not longer, then you have to go through the assessment process, then if you are lucky, you get a diagnosis that allows you to access [government program] and that's not every family...Then even if you are told, yes, you qualify for a (family case) worker, what's the wait list? [Mother 28]

A photovoice submission (see [figure 1k](#)) visualises the onerous process required for remuneration of self-managed respite. These multiple steps and waiting often resulted in families reaching breaking points and exhaustion, as shared by a parent; *application on application and appointments and OT, like it's insane, it's like managing, it's very, very hard.* [Mother 31].

#### Lost in the maze

This theme describes families' difficulties in navigating the respite care system once gaining access to the system. Often families learnt about respite services through various entry points, receiving referrals from for example, schools or clinics. Some parents took system navigation on themselves;

I try to get involved to understand and navigate the system because I think that's how you do it. You learn from other people, you hear things from other people, so they give you the direction and then you start looking for yourself [Father 06].

Others struggled to navigate, often losing their way traversing through one or more of the various government, agency and self-managed respite service options.

Navigation of respite services also required constant vigilance to remain abreast of upcoming transitions. For example, families voiced challenges with the comprehensive assessments required for continued respite as their child aged into adulthood, describing this process as demeaning.

**Table 1** Characteristics of parent and sibling respondents, CYSHCN, and respite care received

Characteristics	Families (N=32)		Parents (N=38)		Siblings (N=13)		CYSHCN of participating families (N=34)	
	n	Per cent	n	Per cent	n	Per cent	n	Per cent
Age at interview (years)								
Range			31–63		6–24		0–30*	
Mean			46		14		13	
Gender identity								
Female			30	78.95	5	38.46	14	41.18
Male			8	21.05	8	61.54	20	58.82
Ethnicity								
Caucasian including Canadian English, Scottish			27	71.05	10	76.92		
Various includes black, Metis, Filipino, mixed, Japanese, Jewish, Somali, Saudi Arabian, Middle Eastern, Persian			11	28.95	s	s		
Educational level/attainment								
Grades 1–8					6	46.20		
Grades 9–12			3	7.89	5	38.50		
College or vocational certificate			8	21.05	s	s		
University (bachelor, masters, PhD degree)			17	44.74	s	s		
Unknown/not disclosed			10	26.32				
Urbanicity								
Urban	26	81.25						
Rural	6	18.75						
Total # of children in home								
1	12	37.50						
2	10	31.25						
3 or 4	10	31.25						
Make up of home								
Two parent	22	68.75						
One parents	10	31.25						
Total family income (\$C annual)								
≤\$C60 000	11	32.35						
\$C60 001–\$C100 000	6	17.65						
>\$C100 000	10	29.41						
Prefer not to answer	7	20.59						
Type of respite care received by family n=32								
Overnight	15	46.88						
In-home	14	43.75						
Provided by informal respite worker (eg, family, friends)	14	43.75						
Out-of-home	10	31.25						
Daytime	9	28.13						
Long term	6	18.75						
Short term	4	12.50						
Provided by trained respite worker	2	6.25						

Continued

Table 1 Continued

Characteristics	Families (N=32)		Parents (N=38)		Siblings (N=13)		CYSHCN of participating families (N=34)	
	n	Per cent	n	Per cent	n	Per cent	n	Per cent
Hours of respite care received (per week) (self-reported)n=34 CYSHCN								
0							6	17.65
1–5							5	14.71
6–12							16	47.06
13–35							7	20.59

\*Some CYSHCN of participating families were dependent on their parents requiring constant supervision and parents defined as a child/youth. The child's parent reflected on respite experiences when their child was younger and up to current times. CYSHCN, children and youth with special healthcare needs.

There was an assessment based to see how much care he would receive and how much funding you would receive for that care and the entire process, I was actually at that meeting. You're trying to make it look like he's as low as possible, so you can get as much care as possible. Like he's not an idiot, he's pretty capable, but we have to sell it as if he is, so he gets money. That's really messed up. [Sibling 02]

Families seeking day programmes for their adult special care needs children ( $\geq 21$  years old), did not always find a suitable option, leaving parents to fulfil multicarer roles.

It's been very hard to work as a mother with a child with special needs. If the services aren't there, I've got to fill that need. So, I'm now her teacher, her health-care provider, on top of her parent, plus now you might as well say her respite care worker. [Mother 11]

#### Undervalued caregiving

This theme describes the difficulty families experienced finding skilled and committed respite workers to provide safe, quality care to their CYSHCN. Low wages, lack of training and respite work not being viewed as a career were cited as the reason for high turnover and scarcity of qualified respite workers. Parents suggested that if respite caregiving were more valued, this role could be considered a career rather than transitional employment.

Caregiving in general isn't really valued. Maybe now, we're seeing the value of it, now during the pandemic, it really is important, but I find if respite work or caregiving could be seen as, could be valued more and the job be paid higher, it would be less of this kind of interim, this job one does in between while they're a student or while they're doing, it could actually be a career. [Mother 25]

Given the MB respite worker wage (\$C11–\$C15/hour) it is challenging for families undertaking self-managed respite to attract, hire or retain respite workers, leading some to 'top up' wages out of pocket. Yet, family members are only granted remuneration for respite services in special circumstances leading to significant frustration.

It's unfair and it is ridiculous. And for some people, that's the only person that they have that's available. Like maybe they live remotely, out in the country. And they have a sibling that lives in the home, but they can't get anybody else. Well, what are you going to do? Like so, to have our hands tied like that is ridiculous and it's not fair... They (family members) know our kids. It's logical to me. And why shouldn't you compensate them like you would anybody else. [Mother 30]

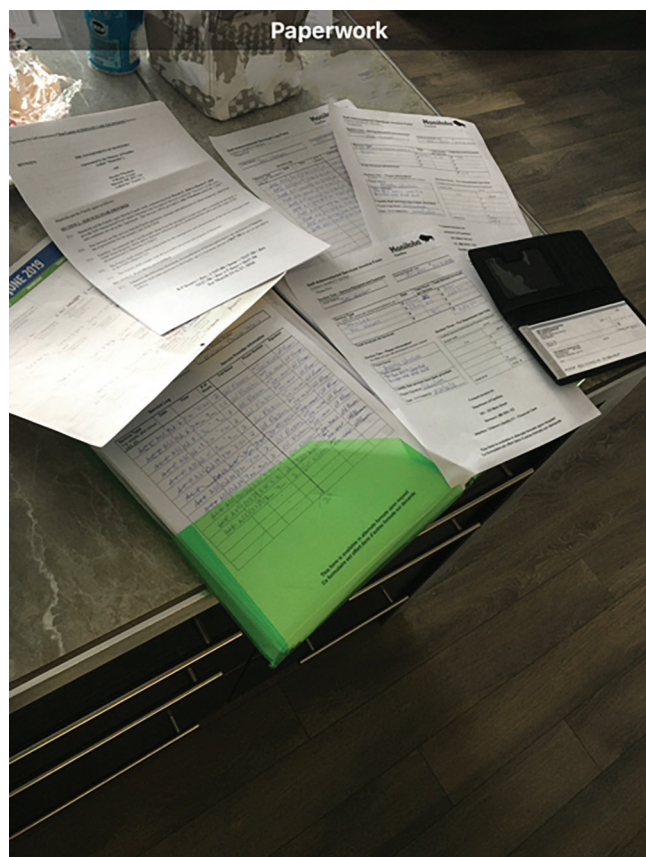


Figure 1 Paperwork.

Consequently, various family members including siblings often provide unpaid respite care.

I would often be left at home to watch her, so I always said I was the unpaid respite ... so I have been like at times like the main carer, the only person at home with her [CYSHCN child] ... And so even though like I always joke like 'oh I'm like the respite worker, I'm the babysitter for "M", like I mean I'm there but it's not like I'm getting paid or anything... [Sibling 04]

### Respite as a lifeline

The respite as a lifeline theme paints a picture of the continuum of impact on families receiving respite care or not.

Despite challenges, respite care services were identified by numerous families as a lifeline, important to their survival, as shared by a mother; *'B's care is so intense, respite is lifesaving. They say that it shouldn't be the most important thing, but it's the only thing that's keeping my family together* [Mother 13]. Siblings noted the importance of respite, granting time for parent couples and speaking to the need for constant care required by families, *I think they like having a break when [Child with SHCN] is out of the house. I am sure they really enjoy it. Especially my mom. She's my sister's 24/7 respite worker* [Sibling 19]. Respite also gave siblings

time with their parents themselves, as described via this ecomap (figure 2 'Restbite' Sibling Ecomap) [Sibling 13].

However, without adequate respite, there was little to no downtime. Feeling as if being in a constant fight added to families' stress and exhaustion, with few able to use respite to recharge.

We are in a constant fight, we desperately need help and there's never enough, never enough. It is very stressful and not easy... It's exhausting to have to prove to higher ups that you are in need of respite. I have to constantly fight and say, you know, we can't do it. That's the worst thing for a parent to say is, I can't do it...and I think we're just a number which is really, really sad. [Mother 13]

Alongside caring for their CYSHCN, many families struggled with underemployment, unemployment, financial stress, sleep deprivation and mental health issues. More concerning, inadequate or no respite services and family exhaustion resulted in some feeling forced to make difficult decisions about the care of their CYSHCN, such as voluntary placement with child and family services (CFS).

For example, the quote below and ecomap (figure 3 CFS Mother 02) by one mother tells the story of a family who were attempting to obtain adequate respite support with their child living with multiple complex conditions including severe aggression.

I think when "R" was about 12 they increased our respite to six hours a week with two staff being present. Um and then and that was because "R" was getting

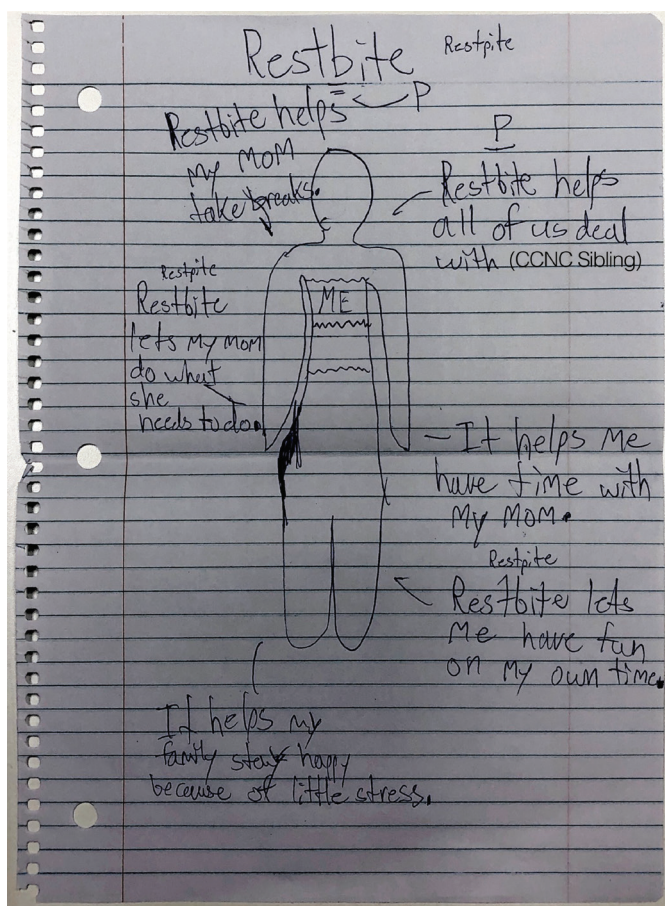


Figure 2 Restbite.

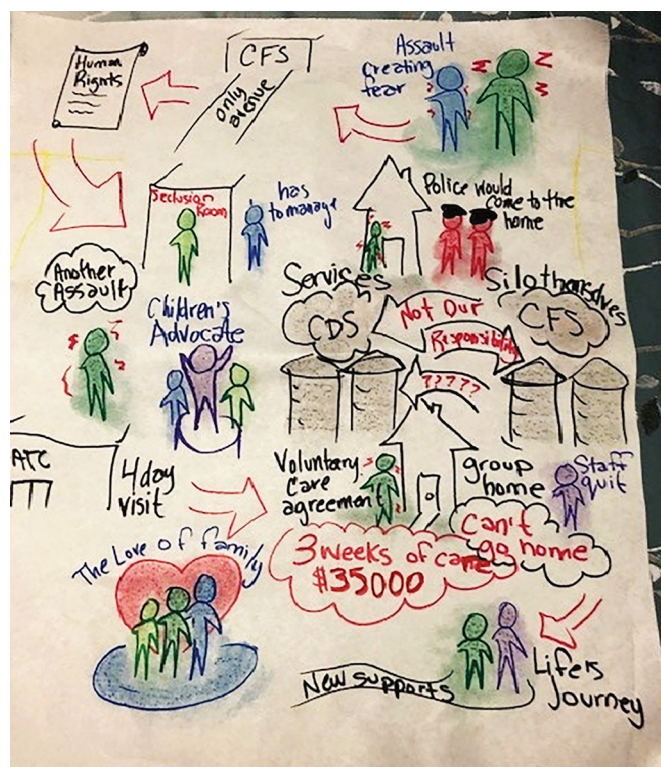


Figure 3 Child and family services.



stronger, there was more aggression. But we were finding that we couldn't manage with those six hours, we were getting completely worn down and it just wasn't enough. So, we did some self-managed respite as well as them um having some respite workers from their agency, And it was quite stressful even then. Um about two years ago "R" severely assaulted me ... And uh at that point we knew that we were really in crisis. ... We took him to the, the Child and Adolescent Treatment Centre, they said that due to "R"'s disability they couldn't admit him, and we had to take him home and we refused. ... And "R" was in care for three weeks and it cost the government \$30,000. ... So, during that time, I was, I was able to, to further advocate saying its going to be \$600,000 a year for "R" to enter care. But our [respite care] plan is at most \$13,000 [a month] [Mother 02 Ecomap]

The ripple effect of an inadequate respite care system and costs to families, government and society was identified. As parents became overwhelmed physically, mentally and emotionally with the all-consuming care of their child, some experienced family breakdown.

It gets tiring. And then you see a lot of peoples' family dynamics fall apart due to stress. It's very stressful you know. I look back at my marriage and, and I think people saw it before I did, but my partner I don't think could, he could [not] cope with this. [Family 11 – Mother & Sibling]

Participants further spoke of the current respite care system as, *a system that again is crisis based, it isn't proactive* [Mother 02] highlighting the longer-term costs of insufficient respite services to both government and society.

If we don't do that [acknowledge impact on caregiver health and wellbeing] as a society and, and decision-makers don't do this, you're going to end up paying for it anyhow. Because these people are going to have

increased mental uh health issues. Uh they're not going to be able to work and do their jobs. They're going to have you know mental leaves, they're going to be on stress leaves. It, it's a ripple effect. [Father 22]

### COVID-19 accentuated the challenges

With the onset of the pandemic, the challenges faced by families were only intensified. The constantly changing guidelines around the pandemic and respite services were difficult for case workers, respite workers and families to interpret, making navigation of respite even more difficult. Furthermore, fear of contracting COVID-19 resulted in some families not requesting respite. Likewise, some respite workers feared entering families' homes and were not mandated to do so as respite workers were not deemed essential during the pandemic. Families felt more isolated and struggled in caring for their children with the loss of respite services as well as friends and families not being able to visit due to safety reasons.

Certainly, during these COVID times, it's just sort of that we have not had any respite or anything, so the last time we had respite was probably mid-February and here it is now mid-June, so certainly the province saved some money because everything shutdown..... Basically for all intents and purpose everything stopped because of COVID...everybody she (daughter) saw before, whether it's her workers, therapists that would come occasionally and all the day program staff. So, unfortunately for "M" (daughter), she lost. [Father 04]

### B: families' recommendations for respite system improvement

Families recommended a multipronged approach to address their experienced challenges with the respite care system. [Table 2](#) highlights the challenges themes depicting families' journeys through the respite care system and how their recommendations for improvement

**Table 2** Families' recommendations to address ongoing challenges with respite care services

Challenges identified main themes	Recommendations	Actionable solutions for respite funders and service providers
You don't Know, what you don't know	Develop an accessible resource hub to guide families, outlining available respite care service entitlements	<ul style="list-style-type: none"> <li>▶ A reference guide</li> <li>▶ A database</li> <li>▶ A website or online App</li> </ul>
Always waiting Lost in the maze	Improve ease of access, navigation and coordination of respite care services	<ul style="list-style-type: none"> <li>▶ Decrease wait times</li> <li>▶ Increase respite hours</li> <li>▶ Overhaul respite care system—is currently a crisis-based system, not proactive</li> <li>▶ Create a one stop shop with a navigator, family advocate</li> <li>▶ Parents and families are experts</li> </ul>
Undervalued caregiving Respite as a lifeline	Develop and designate respite care as a career	<ul style="list-style-type: none"> <li>▶ Provide training and education for respite workers on various disability and behavioural conditions</li> <li>▶ Increase the pool of trained respite workers</li> <li>▶ Increase respite worker wages</li> <li>▶ Provide mentorship for respite workers</li> </ul>

and actionable solutions are linked to the various themes/phases of their journeys.

## DISCUSSION

Using multiple data collection methods, this qualitative arts-based study through the lens of MB families with CYSHCN, underscores the challenges with accessing, navigating and sustaining respite care combined with actionable recommendations for change. Along with interview data, parents' and siblings' ecomaps and photo-voice submissions allowed for creativity, and visualise their perspectives, building a more complete picture of their experiences.

As some interviews included members of the same family, intrafamilial dynamics or disagreements potentially could have arisen, however, this was not experienced in our study. Also, when members of the same family were interviewed separately, there may have been differing perspectives, however, comparisons such as these are beyond the scope of this paper.

Although invitations to participate were sent to families, parental participants in our study were primarily (78.95%) mothers, which may have affected the findings. However, it is relevant to note here that mother-identifying caregivers tend to assume the majority of caregiving for their CYSHCN child,<sup>49 50</sup> and experiences of families with CYSHCN are predominantly expressed through maternal voices<sup>51 52</sup> leaving fewer paternal caregiver experiences to draw from.<sup>53</sup>

Having participants also serve on the family advisory board provided expert lived experience for guiding the study. While advisory board members did have some differing views, they were respectful of differing opinions, quite possibly because they had the shared experiences of caring for CYSHCN. Thus, findings did not change based on Family Advisory input and discussions. A positive outcome of these meetings was the opportunity for members to share with each other and feel support from within the group.

Overall our findings echo evidence from other jurisdictions, noting families' challenges in accessing respite services,<sup>20</sup> waiting across many system checkpoints,<sup>54</sup> understanding entitlements and service options coupled with inconsistent receipt of respite care.<sup>18 22 52</sup> This led parents to become advocates for desirable outcomes, often leaving those without strong advocacy skills unsupported.<sup>55</sup> The disconnect between various private, government, and non-profit service providers, and lack of standardisation further convolutes the respite system.<sup>14 56</sup> Additionally, this study highlights the navigational challenges of respite as CYSHCN transition from daycare to school, to young adult (18+) care. Many of the barriers and challenges to respite care identified by families were present prior to the COVID-19 pandemic but were further exacerbated by pandemic restrictions. It is possible that the pandemic affected the number of hours of respite families received, however, interview questions asked

about past respite as well during COVID-times. Findings specific to respite experiences during the pandemic warrant a separate article.

Unique to this study are families' perspectives that respite care system wait times are primarily due to overloaded caseworkers and respite worker shortages. This may be due to an undervaluing of respite workers, with lack of professional training resulting in higher turnover rates and worker shortages,<sup>24</sup> further exacerbating family stress.<sup>57</sup>

Finally, the family-identified recommendations for a more collaborative, family-inclusive approach to respite services could be empowering, improving well-being for parents.<sup>9</sup> For families who received respite services, it was 'life-saving', while for others, limited or lack of respite care resulted in depletion of emotional, financial and social reserves representing an uphill battle, which many could not afford.

## Limitations

Although families from diverse ethnic backgrounds participated in the study, we did not attain diversity with respect to immigrant and refugee populations, which is warranted, as this population often has delayed access to respite services due to language barriers, and navigation of a foreign system. Thus, we could not make any conclusions on ethnic background. Similar to other studies, fathers' perspectives are also limited in our study. While our intentions were also to involve children with CYSHCN, most were either unable to or declined to participate in the study.

## Implications for clinicians, policy-makers and future research

The findings from our study can be used by clinicians, policy-makers and providers in other Canadian jurisdictions and beyond to address barriers to respite care for families. For example, provide more education on the various physical and developmental conditions which require special medical care to inform planning and practice. Clinicians who are in influential roles can advocate on behalf of their patients for adequate respite care that would support familial health and well-being. Streamlining and alignment of respite assessments, needs and services across agencies and jurisdictions is critical to ensure equitable access and receipt of respite care for families and CYSHCN.

Using findings from the current and previous studies which clearly underline the barriers to respite care and provide recommendations to address these issues, future research in this area should shift to programme evaluation and implementation science, moving evidence-based practices<sup>58</sup> of collaborative, family-centred respite care models into routine usage.

## CONCLUSION

Findings from this study reinforce research exposing an inadequate, minimally funded respite care system as an

issue. The collective disconnects between families and service providers exacerbated by accessibility and navigational challenges, along with undervalued caregiving, and caregiver stress continue to impact the health and well-being of families and their CYSHCN. This study addresses this issue by presenting families' recommendations along with innovative, actionable solutions that can aid funders, clinicians and policy-makers in advocating for and implementing a collaborative, responsive, family-centred system of respite care.

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## Appendix 1: Interview Guides

# Family Member Interview Guide

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### Introduction

1. Could you please tell me a little bit about yourself and your family?
2. Could you tell me more about “name of child with the disability”? How would you describe them?
3. Can you describe what life with “name of child with the disability” is like?
  - What do you see in your child that others may not see?

### Family Life

4. Can you describe what a typical day is like for you and your family?
  - Can you provide me an example of a good day?
  - Can you provide me an example of a bad day?
5. Can you tell me about your child’s relationship with other members of the family (i.e. siblings, grandparents, extended family)?
6. Some parents have shared with us the emotional, physical and mental work that is involved in parenting their child. What does that mean for you?
  - How does that work change throughout the year?
  - How does that work change for you as your child ages/grows?
  - What things make that work easier?
  - What things make that work more difficult?
7. When you think about life with your child, how would you finish the sentence, “If only people knew...”
  - About your child living with ‘NAME OF CHILD’S CONDITION’? About children who require respite care?
  - We’ve heard from some families that other people don’t understand the challenges faced by families of children requiring respite. Is that something you have experienced?

# Respite Sibling Interview Guide

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## Introduction

1. Could you please tell me a little bit about yourself?
2. Could you please tell me a little bit about your family? (Ask them to talk about their relationship with each family member [mother, father, siblings, extended family members, pets etc.]

It is at this point of the interview that you should be asking them to draw the ecomap. The ecomap includes people, places, and activities in their life (good and bad).

### **(On the ecomap – ask them if anything has been impacted because of respite care or lack of respite care)**

*Can you describe your ecomap for me? Who you put where and why?*

## Family Life

3. Can you please tell me what you like to do with your family?
  - First ask as a family unit (i.e., what do you like to do with your family) and then ask for each family member (i.e., what do you like to do with your father...your mother...your brother etc.).
4. Can you tell me about school?
  - What do you like about it?
  - What do dislike about it?
  - Tell me about a time when you had a good day at school.
  - Tell me about a time when you had a bad day at school.
5. What kind of activities do you like to do?
  - What activities do you wish you could do but cannot? Please tell me why?
  - What activities do you do with [name of child who gets respite] that you like to do?
  - What activities do you wish you could do with [name of child who gets respite] but cannot? Please tell me why?
6. Can you describe what a typical day is like for you?
  - Can you provide me an example of a good day?
  - What things/people make it a good day?

# Photovoice Interview Guide

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## Introduction

1. How are you? Do you have anything to add from the last interview we had?
2. Based on your first interview, I have a few follow up questions:
3. Now I would like to review your photos with you.

## Go through each photo and ask the following questions:

- What is Seen here?
  - Describe what the picture is of.
  - What would you title this picture?
- What is really Happening?
  - What is the story behind this picture?
  - If you had to give this photo a title, what would you call it?  
Why?
- How does this relate to your life personally?
  - Describe why you decided to take this picture
  - What does this picture mean to you/
  - How did you feel when you took this picture?
- Why are things this way?
  - What are the reasons that you think this exists?
- How could this image Educate people?
  - What is the main message behind this picture?
  - What would you like to share with the public about this picture?
- What can I Do about it?(What will I or We do about it)
  - What should be done about this?
  - What could be done about this?
- If you could change anything about this (what is depicted in the photo), what would it be?
- How might this look different with/without respite care?