How families of children with complex care needs participate in everyday life

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A B S T R A C T

While we have some understanding of the impact caring for children with complex care needs has on families, little is known about how these families experience participation. This longitudinal qualitative study aimed to extend our limited understanding of how the changing geographies of care influence the ways that Canadian families with children with complex care needs participate in everyday life. The findings in this article focus on parents’ conceptualizations of participation including their perspectives of participation involving themselves, their children, and their family unit. Sixty-eight parents from 40 families took part in the study. Conradson’s (2005) conceptualization of therapeutic landscapes that focuses on the relational dimensions of the self-landscape encounter guided the study. Data collection methods included ethnographic methods of interviewing and photovoice. As a summary of their views, parents within this study described participation as a dynamic and reciprocal social process of involvement in being with others. For participation in everyday life to be meaningful, the attributes of choice, safety, acceptance, accessibility, and accommodation had to be present. Participation was valued by parents because it resulted in positive outcomes. Overall, meaningful participation contributed to them and their children having a life. Having a life referred to being involved in a place where families feel that they belong, are accepted, and are able to contribute to the landscape they participate in. The decision to choose to participate became contingent upon the availability of resources and the parents’ ability to harness them. Harnessing resources referred to the work parents must do to get the necessary resources to make it possible for them and their children to have a life. Having a life for parents required significant physical, mental, psychological and spiritual work by parents. At times the personal resources of parents were so taxed that the possibility for meaningful participation was something less than what they desired. The families’ stories raise questions of societal obligations to promote meaningful participation. This study lends support for further improvements that may enrich the lives of families with children with complex care needs.

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Introduction

Advances in chronic and genetic disease management, health care treatments, and technology have improved the life expectancy of children with congenital impairments, chronic illnesses, and other life-threatening conditions. This has resulted in the emergence of a group of children with complex care needs who have disabilities and often are dependent on assistive or medical technology (Kirk, 2001; Rehm & Bradley, 2005a). These advances have been accompanied by the transfer of care from hospitals and institutions to home settings with parents assuming varying degrees of the complex care and requiring support from both informal (e.g., friends) and formal services (e.g., respite) (Black, Holditch-Davis, & Miles, 2009; Cullen & Barlow, 2004; Kirk, Glendinning, & Callery, 2005). Although reuniting children with complex care needs with their families is considered to be the most desirable option and is viewed by parents as enriching their lives (Carnevale, Alexander, Davis, & Rennick, 2006), it is not without physical, social, emotional, and financial challenges (Carnevale et al., 2006; Carnevale, Rehm, Kirk, & McKeever, 2008; Heaton, Noyes, Sloper, & Shah, 2005; Strunk, 2010). Referred to as “living in a house of cards,” parents have reported experiencing frequent change, uncertainty, and unpredictability in their lives as a result of caring for children with complex care needs (O’Brien, 2001, p. 13). The intense nature of care required by the children can have an effect on the health and well-being of the entire family (Raina et al., 2004). A major focus of children with complex care needs has been the concept of caregiving (Kuster & Merkle, 2004) given the reality that...
the stressors of caring for a child with complex care needs can be overwhelming at times for families (Kirk, 2001). While this work has provided some understanding of the impact that caring for children with complex needs has on families, there is still much we do not know (Carnevale et al., 2008). One such area not fully understood is how families of children requiring complex care experience participation in everyday life. Although there is a growing body of research directed at understanding participation in the context of families and children with complex care needs and disabilities, the research is mainly focused on identifying factors that have an impact on participation (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; King et al., 2003; LaVesser & Berg, 2011; Law, Petrenchik, King, & Hurley, 2007) and on the development of measures of participation (Coster & Khetani, 2008; McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006).

Gaining a deeper awareness of how families with children with complex care needs view participation must be a priority considering participation in everyday life is recognized as critical to feeling confident, establishing meaningful relationships, and attaining life satisfaction (Rosenbaum et al., 2005). Participation in society represents a major goal and vision for many stakeholders, including families of children with complex care needs and health care and rehabilitation professionals (Hammel et al., 2007; King et al., 2002).

Accordingly, we undertook a longitudinal qualitative study that sought to extend our limited understanding of how the changing geographies of care influence the ways that Canadian families with children with complex care needs participate in everyday life. The changing geographies of care refer to the changes in health care service delivery that are the result of the transfer of care from formal spaces such as hospitals towards informal settings such as home (Williams, 2002). Understandably, with the restructuring of health care service delivery models in Canada there is a reshaping of the experience of informal caregivers at home.

To help understand how families experienced participation, the concept of therapeutic landscapes was used to guide our study. First articulated by Gesler (1992) and then further developed by Williams (1999), therapeutic landscapes are concerned with the ways in which landscape or place becomes associated with processes of healing and recovery from illness as well as the maintenance of health and well-being. Landscape or place is considered important as it provides meaning for individuals in many ways including identity and feelings of security (Gesler, 1992) and often involves emotional ties to place and a sense of shared interests and values (Williams, 2002). While the study of the therapeutic qualities of landscapes has focused on the interplay between environmental, social, and symbolic dimensions (Conradson, 2005), we applied Conradson’s (2005) broadened conceptualization of therapeutic landscapes that focuses on the relational dimensions of the self-landscape encounter. In order to understand a particular therapeutic experience, Conradson (2005) contends it is “best approached as a relational outcome, as something that emerges through a complex set of transactions between a person and their broader socio-environmental setting” (p. 338). Landscape experiences are considered therapeutic when they help to develop in individuals a strong sense of belonging and purpose that gives meaning to their lives through attachment to place (Williams, 2002). Therapeutic landscapes provided a unique way to understand how families’ interactions in varied landscapes affected their sense of belonging.

In exploring how families interpret participation, we detailed the perspectives and experiences of children with complex care needs, when possible, and their parents and siblings and identified potential social and ethical challenges that emerge around inclusion and/or exclusion. The methods and findings in this article focus on parents’ conceptualization of participation including their perspectives of participation involving themselves, their children, and their family unit.

Research method

In order to detail the whole story of the families’ daily lives and identify the feelings, meanings, and patterns associated with participation, we chose an ethnographic approach. This longitudinal study was conducted between 2009 and 2011.

Study participants

Families were recruited from the primary integrated health and social services community agency located in a major city in Canada. Children under the care of the agency included those with the most complex care needs and disabilities and that often required some form of technological support (e.g., mechanical ventilation, oxygen therapy). We used a combination of purposive and snowball sampling techniques to be inclusive of experiences of families from diverse backgrounds. Recruitment ended once redundancy or theoretical saturation was achieved. In total, 68 parents (39 mothers and 29 fathers) from 40 families were enrolled in the study. The age ranges for mothers and fathers were 22–56 years and 28–55 years respectively. Fifty-eight parents were either married or in a relationship. One family had two children with complex care needs for a total of 41 children with complex care needs. In addition to the child with the complex care needs, 30 (75%) of the families had at least one other child.

The age range of the children with complex care needs was between 6 months and 26 years with the mean age of 10 years at the time of the study. Nine (22%) of the children had a primary diagnosis of cerebral palsy. The primary diagnoses for remaining children varied and included developmental disorders (e.g., global developmental delay), seizure disorders, terminal cancer, chronic lung disease, genetic disorders (e.g., Down syndrome), and congenital disorders. Table 1 provides a description of the children with complex care needs.

Data collection

Data collection commenced in January of 2009 with the goal of interviewing parents at three time points: at the start of their entry into the study, midway through, and prior to their exit from the study. The in-depth, open-ended interviews explored their understandings and experiences of their and their child’s participation within the context of caring for a child with complex care needs, and were spread out over a period of 12–18 months in order to better understand whether parents’ perspectives of participation changed over time. Examples of questions asked of parents included how they defined participation, how participation changed for them and their family since caring for their child at home, what it meant to them to participate in everyday life, and the types of activities that they participated in.

Although an interview guide was used, the open-ended interview technique provided parents the opportunity to focus their responses on areas considered important to them or areas previously not anticipated by the researchers (Barbour, 2008; Morse & Field, 1995). Additional questions based on the emerging data analysis were added to the interview guides for the second and third interviews. Interviews were conducted primarily in the families’ homes. Each interview lasted from 90 to 180 min and was digitally recorded and transcribed verbatim. Field notes were recorded to describe the context (e.g., participant’s non-verbal behaviours, communication processes) and the interviewer’s perceptions of the interview.
To facilitate discussion during the first interview, parents had the opportunity to draw an ecomap. An ecomap is a graphic portrayal of social relationships and networks between individuals or families and places and settings (Rempel, Neufeld, & Kushner, 2007). Rooted in family therapy and clinical family nursing practice with families, the use of ecomaps is increasingly being recognized as a valuable research tool in family research to help facilitate an understanding of the nature of the bonds and degree of connectivity within social networks. In this study, participants were asked to draw a circle that represented themselves and then asked to draw additional circles representing people, activities, and places that are a part of their lives. Participants were then asked to draw lines between the circles that indicated the degree of connection between each person, activity, or place. Different types of lines were used to represent different types of connection (e.g., a thick line indicated a strong connection). Finally, parents were asked to reflect on the changes to their ecomaps during the second and third interviews.

Use of photovoice complemented the second interview session, which was conducted midway through the data collection period. Photovoice is a participatory research method whereby individuals can address important issues through photos and discussion (Wang & Burris, 1997; Wang & Redwood-Jones, 2001). Parents were given digital cameras and asked to take pictures of objects, people (if they obtained permission from them), places or events that depicted their thoughts and feelings related to their and their families’ participation experiences. After the photos were taken, parents were interviewed by means of the SHOWeD method (Dahan et al., 2007; Strack, Magill, & McDonagh, 2004), an approach that encourages discussion with participants on the meaning of the photos. The SHOWeD method involves leading individuals through photos by asking them to identify what they see, to describe what they think is happening in the photo and to explain how the photo relates to their lives by delving into why and what can be done about it. During the second interview, parents were asked to talk about what the photos meant to them in terms of participation. In addition, parents were asked follow-up questions based on their initial interview and to comment on any changes since the first interview, including any changes in how they participated in everyday life.

The focus of the third interview session was to assess the changing nature of participation over time. Questions asked included what changes in general had occurred in their lives, how participating in everyday life had changed for them since taking part in the study, and whether participating in this research study had resulted in any new reflections or thoughts about what participation in everyday life meant to them.

Although the intent was to interview parents three times, not all parents were able to continue with either the second and/or third interview due to scheduling difficulties. Parents from 29 families participated in the second interview sessions and parents from 20 families took part in the third interview sessions.

Data analysis

All data emerging from interviews, photographs, ecomaps, and field notes informed data analysis. Several iterative steps of analysis, congruent with ethnography, took place (LeCompte & Schensul, 1999; Roper & Shapira, 2000). The first step involved isolating items or patterns, followed by organizing patterns and identifying attributes for each of them. The last step involved the discovery of relationships among the patterns to create themes. Data from the first set of interviews were compared with the second and third set of interviews, and themes were refined. Measures to enhance methodological rigour included prolonged engagement with participants and data, careful line-by-line analysis of the transcripts, and detailed memo writing (Lincoln & Guba, 1985). Preliminary interpretations were also discussed with parents during the second and third interview sessions, which helped to uncover and lend support for the emerging essential themes.

Ethical considerations

We received permission to carry out the study from the Education/Nursing Research Ethics Board at the University of Manitoba. Informed consent was obtained from all parents. Throughout the study we strived to ensure that ethical standards were maintained including safeguarding participants’ privacy. This included informing all participants that the photos would be handled like any raw data in that any information that could possibly identify them or others in the photos would be removed (digitally altered).

Findings

Parents’ understandings of participation for them and their children were represented by four themes: Meaningful

<table>
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<tr>
<th>Characteristic</th>
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<tbody>
<tr>
<td>Gender</td>
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<td>&gt;21 years</td>
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<td>Education</td>
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<td>Daycare/nursery/ preschool</td>
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<tr>
<td>Special classroom school</td>
<td>8</td>
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<tr>
<td>Graduated (working)</td>
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<td>Cognitive</td>
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<tr>
<td>Sensory</td>
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<td>Emotional/behavioral</td>
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<td>Types of technology used</td>
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<td>Feeding tube</td>
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<td>Mechanical ventilation</td>
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<td>O2 Therapy</td>
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<td>Wheelchair</td>
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<td>Suctioning</td>
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<td>Lifts</td>
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<td>Walker/stroller/bike/stander/cart/chair</td>
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<td>Catheter</td>
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<td>Special bed</td>
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<td>Braces</td>
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<td>Speech device</td>
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<td>Number of technology/devices used per child</td>
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participation, Having a life, Harnessing resources in the changing geographies of care, and Participation as something less.

**Meaningful participation**

Although participation varied between and within families, the shared essential essence of participation for families as perceived by all parents was that it was equated with a sense of being a part of something and/or being involved in something. Regardless of ethnic background or income status, parents reinforced that participation was different than activity or being active. Whereas the International Classification of Function Disability and Health (ICF) defines participation in terms of an individual’s involvement in life situations with an emphasis on capacity and performance (World Health Organization, 2001), while parents in our study placed more emphasis on the “being” rather than the “doing.”

Um, being involved. You know, being a part of something, being a part of a group, you know, whether it’s Boy Scouts or a service group or, you know, volunteering for something (Mother 21).

Parents of children with limited mobility, cognitive, and communication abilities believed their children experienced engagement or involvement by just being.

Um, you know, if the girls are involved in something and we can at least take “J” (daughter with complex care needs) there to hear...and just hearing a crowd to listen to, but “J” being able to be in situations like that where she’s hearing what’s going on. Uh, I think that’s participation, being able to...but being able to take her to a public park where my other children go skating, and I sit inside where it’s warm but she’s still out with us. So as long as she’s around what’s going on I think that’s what I consider participation (Mother 1).

Parents reinforced that participating in some activity or place in and of itself did not always qualify as meaningful participation. This finding is consistent with the work by King, Petrenchik, Law, and Hurley (2009) that examined participation of children with and without physical disabilities in formal and informal activities. In their work it was revealed that children without disabilities reported significantly greater enjoyment of formal activities compared to children with disabilities. Moreover, children with disabilities participated in significantly fewer formal and informal activities and participated in these activities less intensely than did children without disabilities. King et al. argued that the act of participation does not guarantee that individuals are engaged in a meaningful way.

For participation to be meaningful, a number of attributes that contributed to a sense of comfort and trust had to be present. First, participation had to involve some choice. Parents felt that even children with limited cognitive abilities needed input into the activities they could participate in. Parents relied on their children’s non-verbal expressions to assess their children’s level of comfort when participating in activities, and if they showed any signs of distress or discomfort, parents would remove them from the activities.

“Feeling safe” or the element of safety within the landscape was also necessary for participation to be meaningful. Parents expressed the importance of participation occurring in safe places or spaces that were not dangerous physically or emotionally, which supports the notion that a sense of safety is an important prerequisite for relational encounters (Conradson, 2005). Similar to the findings of Rehm and Bradley (2005b) on the social consequences of raising children who were medically fragile and developmentally delayed, engagement in meaningful activities was more successful for parents and their children when landscapes felt safe and comfortable. When safety and comfort were not present, families limited their participation by choosing to stay home, socializing with a very limited group of friends or relatives. While safety was always considered, some parents expressed that sometimes it was important to allow children to partake in activities that involved some risk.

I would say for us participation means like it is something we want to do, we’re going to go do it. Um, like I’ll take responsibility if something happens... She (child with complex care needs) taught herself to swim. And we got in trouble for it a few times from the doctor, because she’s trached (tracheostomy) she shouldn’t be in the water. But she sticks her finger in her trach. Just immerses herself completely underwater and swims (Mother 13).

Hammel et al. (2007) concluded that risk taking is closely tied to choice and control over the decision of how and when to participate, which held true for the parents in this study. Some of the landscapes children participated in had both positive (e.g., choice and control) and negative (e.g., risk) elements. This finding is reflective of the work of Collins and Kearns (2007) on New Zealand beaches that revealed that beaches possessed both health-giving and health-endangering properties. Conradson (2005) reinforces that taking risks allows an individual to extend oneself; however, to do so there must be a certain degree of trust in the place where participation occurs.

Parents reinforced that meaningful participation required others to understand and accept them and their children. This included understanding their circumstances and the different ways of being as a family. It was important to parents for others to “to get their child” or “know their child” rather than label their child. Meaningful interaction was possible in those landscapes when inclusion was promoted. However, parents found that lack of acceptance due to a lack of knowledge and understanding of the child’s condition was one of the greatest barriers to achieving meaningful participation. This finding is consistent with other studies on participation that show individuals with complex care needs and disabilities are unable to interact meaningfully in unfavourable places and settings (Hammel et al., 2007; Harding et al., 2009; Law et al., 1999; Tsai & Fung, 2009). Participation in activities where others did “not get who they were” resulted in parents feeling like the foreigner or “the other.” Parents did not feel a sense of trust in those individuals who were not understanding of their child. Unless trust is well established, there is the potential for families to avoid participation, possibly leading to alienation and social exclusion (Emira & Thompson, 2011). In dealing with a lack of understanding, parents reinforced the importance of having a planned exit strategy.

You have to make sure that people are very understanding. You just make sure people understand who “A” is or they’re forgiving for his behaviour. ’Cause you’re always going to have something that might go wrong. ’Cause you’re always preparing. You are thinking like that it is in the front of your head, thinking it is there. You are just like, “okay something might happen, depending.” You could be out in public and he might have a meltdown. We must just remove him from it (Mother 21).

Accessibility was also essential for participation to be meaningful. Places, spaces, activities, and situations had to be easy to move in and out of in order to be considered accessible. The notion of a spatial dimension to participation became very clear to the parents when they and their children could not participate because they could not access a place (Coster & Khetani, 2008). Parents reinforced that families of children with complex care needs should be able to access the same places, spaces, activities, or situations that “able bodied people” have access to. However, all parents had...
had experiences with accessibility as “something missing” and far from the ideal as reinforced by the following:

> Just like the accessibility thing, so many times we go places and they’ll say that they’re wheelchair accessible but they’re not. Or they’re only partially wheelchair accessible. Like when we went bowling, the alley said, “Oh yeah, they were fully, they were wheelchair accessible, yeah, we could get in there.” But you had to walk up the steps to get to the bowling lane. You know, like we’re this close, right? (Mother 5!)

In recognition that most places, spaces, activities, or situations were less than ideal with respect to being accessible, meaningful participation necessitated others to be accommodating and flexible. As Emira and Thompson (2011) note, places that are flexible can contribute to a parent’s peace of mind. In contrast, inflexibility results in additional concerns for parents that may cause them to think twice about participating. Parents appreciated when individuals or systems took into account their children’s unique needs and made changes that would make meaningful participation possible for them. This included a father of a boy who described how his son’s school created a place or landscape that made it possible for his son to attend school.

> The room is all set up (pointing to the photo of the room), it has a track system in it, a washer-dryer, a tub, a roll-in shower, an accessible toilet, accessible sink and then there’s a change table where it goes up and down. They’ve also managed to fit a … bed in there for him because next year with long days we don’t know how he’s going to handle it. So they have a bed for naptime. So his days are going to be longer as of this next coming school year. Um, he’s the first with severe special needs (Father 7).

**Having a life: the value of participation**

Overall, parents valued meaningful participation as it contributed to their sense of having a life. Having a life referred to being engaged or involved in a place where families feel that they belong, are accepted, and are able to contribute to the landscape they participate in. By engaging in meaningful participation, an enhanced sense of well-being was possible. Parents experienced meaningful participation in those places that had restorative qualities. However, Conradson (2005) acknowledges that it is not only the restorative qualities of a place that are important, but the fact the restorative qualities can be experienced differently by different people.

Parents valued participation because it resulted in a number of positive outcomes. They identified a number of positive outcomes resulting from meaningful participation similar to those reported by Goodwin and Staples (2005), Hammel et al. (2007), and Harding et al. (2009). First, parents viewed participation as integral to their child’s development and for preparing their child for the future. The more children experienced meaningful participation, the more prepared the child would be for the future. Meaningful participation helped children to develop their sense of self with respect to increasing their confidence and sense of mastery as one mother noted about her daughter:

> Like for her, I guess when I’m relating it to her, it is like mastering, being in that situation, like going to church and feeling confident. She’ll just go up and grab a flag and go down with the other kids. Like she’s mastered being on her own there (Mother 13).

For parents who had little opportunity for meaningful participation in therapeutic landscapes, their narratives reflected a diminished sense of self. Participation was also considered central to the family’s identity. By partaking in more family activities that were viewed to be meaningful, a greater sense of family emerged. Parents noted that meaningful participation afforded them the opportunity to make connections with other individuals. Connection, as one parent noted, “was a big part of the human experience.” The connections or relationships with others evoked a sense of belonging in parents and children. Places, situations, and events that promoted understanding and acceptance contributed feelings that they belonged.

Parents also reinforced that through meaningful participation it was possible to have a purpose in life and to share and give back to others; a sense of reciprocity was realized. In turn, this resulted in good feelings about one’s self.

> Well, I guess it means that we are contributing to the community as well as being supported by it. We need more support from our community than most people do, but we also feel that even if we didn’t need more support, a citizen has an obligation to his or her community to participate in it, to give to it as much as possible. And we feel very strongly that it is important to have both the confidence that your community is standing behind you and that you are able to make a contribution to the community and stand behind your neighbours (Father 14).

Parents reinforced the belief that participation is a responsibility: “a responsibility to oneself and to one’s family, community and society in general” (Hammel et al., 2007, p. 8). Even participating in this study was seen by parents as a means to giving back to society and helping other families raising a child with complex care needs. Parents believed that even if their children were unable to communicate or be “doing” activities, their children nonetheless contributed to society by their presence in school and other community activities. Parents believed that children with complex care needs contributed to society in that they taught others to be more caring and empathetic and helped others in their development. Stories of the positive impact that their children had on their classmates such as the following one were not uncommon:

> This year my son went from the elementary to junior high this year, so this is a brand new school for him. … And his classroom teacher had been telling me that there is a group of kids sort of headed by one of the cool kids in class, one of the cool guys, would be considered I suppose by his peers. He didn’t know “M” from, he went to a different school for elementary, but apparently he has taken a real interest in “M” and he has grown quite fond of him and he will spend time with him in the classroom and read to him and that sort of thing. And that sets the tone because he’s one of the classroom leaders is what the teacher had said to me, that has set the tone for the others (Mother 2).

**Harnessing resources in the changing geographies of care: conditions affecting meaningful participation**

The decision to choose to participate was contingent upon the availability of resources and the parents’ ability to harness them within the changing geographies of care. Harnessing resources referred to the work parents must do to access the necessary resources that made it possible for them and their children to have a life. The availability of the right resources made it more possible for families to access and participate in desired places, spaces, activities, or situations. While the resources varied, a number of resources including suitable transportation, respite, financial support, assistive devices, support from friends and family members, and housing were identified by parents as especially helpful.

In order to harness resources parents not only had to become experts about their children’s unique and changing needs, but also had to finesse an understanding of the complex and dynamic social,
health, and education systems. As such, parents had to employ a number of strategies such as advocating for their children, figuring out the system, and teaching others. Parents became a “tag team,” with one parent often leaving employment to engage in the demanding multi-dimensional responsibilities and roles in caring for their children. The parents’ ability to become experts was shaped by the landscapes they interacted in and whether or not the landscapes fostered parents’ ability to care for their children. When the landscapes were less accepting and helpful, parents were less able to harness resources. Moreover, experiencing barriers to services created distinctly non-therapeutic landscapes for parents. The physical, mental, psychological, and spiritual resources of parents were crucial determinants of the family’s ability to harness resources. However, the demands placed on parents in harnessing resources constantly challenged the parents’ own resources thereby impacting how they and their children participated in everyday life.

Because we’d love to take him to Tinker Town just to ride on the train and go on the merry-go-around and have some cotton candy and, but, you know, it’s just such, it’s just such a chore to try to figure out how we’ll work it with “K” (child), and with “K’s” feeding schedule, and with is “K” going to be in a good mood? or, you know, so... It’s hard to get the energy up and, and you know it always sounds so wimpy, but, but it’s true, like some days we’re just coping, you know, we’re just coping, lack of sleep and stress (Mother 18).

Harnessing the right resources often involved the interplay of a number of elements within landscapes that included individual or personal (e.g., parent’s health), social (e.g., supportive extended family member), physical (e.g., accessible playgrounds), institutional (e.g., school policies), and economic (e.g., financial supports) elements. For example, the availability of adequate transportation was often contingent upon parents having the finances to purchase specialized vehicles. Parents repeatedly shared stories and photos of the ongoing problems of harnessing adequate transportation and parking.

I think the community as a whole has accessibility issues...public parking is a real problem for people with disabilities because we’re going increasingly to parking structures, which have inadequate overhead clearance for any type of wheelchair van... They’ve got a whole row of wheelchair spots in the parking structure, but nobody who has to have a raised-roof vehicle can get to them (Father 14).

Another example of how harnessing resources was contingent on the interplay of multiple factors was the availability and use of assistive technologies and devices. While there were photos depicting how assistive devices enhanced accessibility, there were also photos of how the devices were not being used to their full capacity. Parents talked about negative experiences that were in part due to indoor and outdoor places lacking the proper resources necessary to support assistive devices.

We can’t take him to any outdoor activities because we can’t rely on pathways and sidewalks to be passable via wheelchair. We can’t take him to the nature retreat, for example. We can’t move him around easily, even with the wheelchair van we can’t easily get him from where we would have to park to the place, and it’s very difficult, physically demanding to push him across the, the landscape...it’s impassable (Father 14).

Parents in this study also reported a lack of sleep and enough time for self as impacting their ability to harness resources, which in turn effected how they experienced participation. Additional factors impacting parents’ ability to harness resources have also been reported in other studies (Ceglowski, Logue, Ullrich, & Gilbert, 2009; Emira & Thompson, 2011; Law et al., 1999), including some parents not knowing what resources were available to them, or having difficulty in gathering information on the resources. Past research identified cost of resources (Emira & Thompson, 2011), deficits in the amount of resources available to them (Wee & Paterson, 2009), communication barriers between services providers and families, and negative attitudes of others (Howell & Pierson, 2010; Law et al., 1999; Tsai & Fung, 2009; Wee & Paterson, 2009) also made harnessing resources difficult.

The changing geographies of care had an effect on the amount of time, degree of energy, and intensity of planning required to harness resources by parents. Physically-demanding care as well as less physically demanding care that was unpredictable and uncontrollable resulted in parents expending their personal resources. Setbacks in the children’s health status placed additional demands on parents, whereas improvements provided some relief for parents. Likewise, although growth represented survival, thriving and development, it also resulted in new challenges, including increased care demands. Most of the children transitioning to adolescence and adulthood continued to be highly dependent on their parents.

Participation as something less: quality and quantity of meaningful participation

The quality and quantity of participation varied among the families as reinforced by the number and type of relationships representing places and people on the families’ ecmaps. In the end, some families got there more easily (i.e., they felt they had a life) while others struggled to participate. For some families, participation was only possible in places that were in close proximity to the family home. Generally these families had fewer places identified on the ecmaps. There were also those families who identified the family home as the only landscape that instilled a sense of belonging (see Fig. 1). This was particularly true for those families where parents had trouble harnessing resources. In contrast, families who were able to harness the appropriate resources identified more landscapes that contributed to a sense of belonging (see Fig. 2).

Similar to what was reported by Raghavendra, Virgo, Olsson, Connell, and Lane (2011) and Solish, Perry, and Minnes (2010), parents in this study revealed their children with complex care needs had, for the most part, participated in fewer social, recreational, and leisure activities with their peers compared to children without complex care needs, and also were more likely to participate in landscapes closer to home. Opportunities for the family unit to participate together in activities were also limited with family members more likely to engage in activities by themselves and not as a family unit. It was as if two families existed within the overall family unit for some families: the family of the parent (usually the mother) with the child with complex care needs and the family of

Fig. 1. Home as the only landscape.
the father and siblings (Woodgate & Degner, 2004). For example, one mother describing the opportunity to go on a family trip expressed,

I know at one point we’d like to take the kids to Disney World but I don’t know if we’ll be able to go with “A” (child with complex care needs). I don’t know if it’s going to be my husband and “C” (other child) going on the trip and that’s very upsetting for me (Mother 2).

The need for intense planning also resulted in participation that often lacked any spontaneity as one mother reinforced,

It’s long-term planning. You just can’t on the spur of the moment say, “what are we going to do tonight” or say “we’re going to go to a football game tonight!” it doesn’t, our life doesn’t work like that (Mother 17).

For some families participation revolved around the hospital world due to the considerable activities related to the “so many appointments and hospitalizations” necessary in addressing the children’s complex care needs. Attending appointments required a lot of energy particularly given transportation and accessibility challenges in getting to and from the appointments. At times the parents became so taxed that the possibility of meaningful participation was minimal. This was also the case when the child’s care needs became particularly overwhelming. When the amount of time, degree of energy, and intensity of planning required harnessing resources that became overwhelming or too much for parents, it was less likely that parents would choose to participate in desired places, spaces, activities, or situations. For those families where participation was experienced as something less than desired by parents, family life was described as being more passive whereby they experienced a sense of mourning for family relationships that had not been nurtured. Parents described landscapes that were less than desirable because of disappearing friends and family and “using up” extended family members. As a result, the differing social relations that transpired shaped parents’ health and well-being. For some parents, having a life was placed on hold as this one mother reinforced:

I have no life. I used to volunteer with Big Sisters and yeah I did the church stuff. Yeah everything has stopped…. My life revolves around “M” (child with the complex care needs) and what has to be done with him. I had my life before and I’ll have it later on way in the future (Mother 28).

However, there were some families who described themselves as “having a life” as a result of being involved in places, spaces, activities, or situations. Parents in these families were able to harness the resources (their own and also external resources). Nonetheless, even those families who described themselves as “having a life” experienced participation in smaller degrees. For example, one family opted for a three-day camping trip after acknowledging their preferred seven-day camping trip was not possible. Overall, participation for parents in this study was best described as “something less” than what they would have wanted or desired for themselves and their children.

Discussion

While there is a growing body of research that has examined caregiving in families of children with complex care needs, very few studies have focused on the meanings family members, including parents, assign to participation in the context of the changing geographies of care. By applying Conradson’s (2005) conceptualization of therapeutic landscape in our study, we were able to arrive at a deeper understanding of how families interpret their participation within varied socio-environments. The findings reinforce that encounters between “an individual and a landscape are understood as being complex and multifaceted, emerging out of particular embodied encounters but also subject to later interpretation” (Conradson, 2005, 338). For parents in this study places that promoted a sense of belonging were not only contingent on social encounters (human to human), but also on encounters between people and things (e.g., assistive technology, vehicles), as well as people and other biological entities (e.g., outdoor spaces) (Conradson, 2005).
Use of photovoice enhanced the parents' narratives by providing us with visual images of their (the insiders') viewpoints, at a specific moment in time (Szto, Furman, & Langer, 2005). The ecomaps added to our understanding of context in which participation did or did not take place.

Parents experienced and described participation as a dynamic and reciprocal social process of involvement in being with others. The many factors impacting the quantity and quality of participation for the families reinforces the premise that participation is a multifaceted concept that is not simply an event or mission but a process (Lolichen, Shenoy, Shetty, Nash, & Venkatesh, 2006). For the parents in this study participation was reflected in their values and what was important to them, and not by a set of activities or rules prescribed by society (Hammel et al., 2007; Wee & Paterson, 2009). This finding further reinforces the need for not only objective participation assessment measures but also subjective and values-based measures (Hammel et al., 2007).

Similar to the findings of other studies (Hammel et al., 2007; Harding et al., 2009; Law et al., 1999), meaningful participation required the attributes of choice, acceptance, safety, accessibility, and accommodation. The parents in this study viewed these attributes as essential to securing a sense of trust in the landscapes where participation occurred. Parents became more guarded in participation experiences that lacked any of these attributes. Research has shown that in situations when there is a lack of trust between parents of children with complex care needs and their children's health care professionals, parents feel it is necessary that they assume more responsibility for their children's care (Fereday, Oster, & Darbyshire, 2010). While trust and the parent-health care professional relationship have been a focus of research for families of children with complex needs, the nature of trust has not been well articulated in context of participation by families with complex care needs.

Participation has been deemed essential to promoting an enhanced quality of life (Coster & Khetani, 2008), which was congruent with what parents revealed in our study. Parents equated meaningful participation with having a life. They acknowledged the many positive outcomes of participating in everyday life. Through self-landscape encounters, there is the potential for the emergence of new dimensions of selfhood (Conradson, 2005). Participating in everyday life contributed to a strong sense of self, sense of belonging, and having a purpose in life, all vital elements to human existence. Especially important to parents was how participation contributed to the personhood of their children. Parents felt that participation contributed to the development of skills and competency in their children. Bult et al. (2011) further contend that by being active and engaged in activities of interest to the individual, the development of physical and social skills and the exploration of personal interests are fostered. Opportunities to participate provide individuals with the ability to fully explore their potential in all aspects of life including intellectual, social, emotional, and physical aspects (Bult et al., 2011).

Realizing the many benefits to meaningful participation, parents struggled to ensure that their children had a life. Parents had to learn how to negotiate participation for them and their children in landscapes where barriers still exist. Of all barriers, social and attitudinal still remain the biggest roadblocks for them and their children (Law et al., 1999). Having a life was more difficult to achieve in those families in which parents had trouble harnessing the resources that made participation possible. Each parent's personal resources were challenged by diminished sleep and adequate time for self and partner. Too many families in our study still experienced feeling like an outsider in their attempt to participate in desired places. As Carnevale et al. (2008) note, the challenges and barriers faced by families of children with complex care needs can restrict inclusion, leaving some families relatively housebound.

Despite changes that have occurred over the last decade to help support the participation of families of children with complex care needs, more needs to be done. While solutions exist to enhance accessibility for families, exclusionary behaviours, bureaucratic inflexibility, inequitable policies, and stigmatizing practices prevent solutions from being implemented (Carnevale et al., 2008; Law et al., 1999). As well, the interests of families as a whole are minimally considered and ethical considerations tend to be limited to significant, episodic decision-making moments (Carnevale et al., 2008). To redress the inequities, Hall (2007) believes society needs to reclaim the agenda and focus on social structures and places, wellbeing and empowerment. Labonte (2004) contends the disadvantages experienced by families of children with complex care needs are “seen to lie in their exclusion, rather than in excluding structures, for which the solution is targeted efforts at remedial inclusion rather than more systemic reform of economic practices predicated on inequality” (p.117). Accordingly, Labonte (2004) reinforces that the focus should include the socio-economic values and government that create exclusion as opposed to a focus solely on the groups and conditions excluded.

Limitations

Our study involved families of children with varied complex care needs; therefore, future research studies focussing on families of children with specific or particular complex care needs may result in differing and additional perspectives. As well, the majority of participants were of European descent and thus exploring insights into the perspectives of those with different ethnic backgrounds would be important. Accessing service providers and professionals from social, health, and education systems would also help to provide context to families’ experiences.

Conclusion

As parents of children with complex care needs harness resources in the changing geographies of care, it is clear that they do so with a commitment to family and their children’s human potential. Their efforts benefit society by broadening our collective human experience. Yet the question remains: Will society be there to assist growing numbers of families of children with complex care needs as they struggle to have a life?

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