

Siblings of children with complex care needs: their perspectives and experiences of participating in everyday life

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Summary

Background Participating in everyday life is essential to the healthy development and emotional well-being of children. However, little is known about siblings of children with complex care needs (CCN), and their perspectives and experiences of participating in everyday life. The aim of this paper is to present research findings that add to our understanding of how siblings of children with CCN view and experience participation in everyday life.

Methods To arrive at a detailed and accurate understanding of the siblings' perspectives and experiences, we used the qualitative research design of ethnography. Sixteen siblings (seven brothers, nine sisters) of children with CCN were recruited. The siblings ranged in age between 7 and 25 years, with a mean age of 14 years. All siblings took part in opened-ended interviews and completed ecomaps to describe how they participate. Five siblings also took part in the photovoice method. Analysis involved several iterative steps, congruent with ethnography.

Results Four main themes emerged as follows: (1) participation is about being part of a group; (2) it feels good; (3) I love my sibling but...; and (4) promoting participation. Siblings of children with CCN identified challenges to participation and also described ways that they participate that relate to the care of their sibling.

Conclusions Siblings prioritized the relationship with their sisters and brothers with CCN in their life, and a great deal of their participation was chosen with their sibling in mind. Sibling-to-sibling relationships were distinct and meaningful and, as a result, participation was always done mindfully and with the family needs at the forefront. Nonetheless, clinicians caring for children with CCN must keep in mind the challenges that siblings of children with CCN experience and provide strategies to siblings that will help to promote their participation in everyday life.

Keywords

Canada, children, complex care needs, families, participation, siblings

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Introduction

Children with complex care needs (CCN) are those with chronic physical and mental illnesses and disabilities, who require multiple health and related services from a variety of sectors at multiple locations (Cohen *et al.*, 2011; Schoen *et al.*, 2011;

Burnside, 2012). The shifting geographies of care of these children from more formal public spaces (e.g. hospitals) to informal private settings (e.g. the home) have had a significant impact on the family unit and the relationships within those families, albeit in multiple and varied ways. Families caring for children with CCN adjust to daily life in an attempt to

develop routines and lifestyles, which permit them to resemble other families (Hewitt-Taylor, 2008; Prchal & Landolt, 2012).

Within the family, siblings are the first peer group experience (Caplan, 2011), and the sibling relationship is among the most significant influences shaping life course experiences, social-cognitive development, and identity formation (Goeke & Ritchey, 2011). Interactions between siblings, including conflicts, contribute to the development of social and emotional capacities, skills and behaviours (Whiteman *et al.*, 2011; Giallo *et al.*, 2014). It therefore follows that siblings of children with CCN will be affected by their sibling relationship in ways that other siblings are not (Burke, 2004). Siblings may face a range of feelings including fear, shock, concern and helplessness when witnessing the physical and emotional pain of illness experienced by their sibling with cancer and other chronic illnesses (Woodgate, 2006; Besier *et al.*, 2010; Prchal & Landolt, 2012). Although a majority of siblings are well adjusted, they are at risk for developing negative emotional and behavioural problems, and sibling adjustment is intricately linked to family functioning in families of children with CCN (Lowes, 2007; Goeke & Ritchey, 2011).

Despite the integration of siblings into family-centered approaches in recent years, an aspect of the lives of siblings of children with CCN that is rarely addressed in the literature is their own perspectives on participating in everyday life activities. This is a concern considering participation in everyday life is essential to the healthy development and emotional well-being of children (Axelsson *et al.*, 2013), and young people affected by chronic illness are more likely to experience challenges to participation (Harding *et al.*, 2009). Accordingly, if we hope to improve the lives and well-being of brothers and sisters of children with CCN, there is the need to address and amplify the typically unheard voices of brothers and sisters of children with CCN about their perspectives and experiences of participation. The aim of this paper is to present research findings that add to our understanding of how siblings of children with CCN view and experience participation in everyday life. The findings are derived from a 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 CCN participate in everyday life.

Methods

Design

In order to be inclusive of the perspectives and experiences of each sibling, we used the qualitative research design of

ethnography. The inductive nature of ethnography afforded the opportunity for siblings to make emic descriptions about what they think about and experience with respect to their participation in everyday life (Spradley, 1979; LeCompte & Schensul, 1999; Roper & Shapira, 2000).

Participants

This study took place in a major city in Canada. Using purposive and snowball sampling techniques, we recruited 40 families of children with CCN from the major primary health and social services agency responsible for providing services to children with CCN. While this paper is focused on the siblings' perspectives, parents' ($n=68$) perspectives were described in a previous paper (Authors' reference). In total, 16 siblings (seven brothers and nine sisters) chose to participate in our study. The siblings came from 12 of the 40 families in the study with three families having more than one sibling taking part in the study ($n=3$, $n=2$, $n=2$). All 16 of the siblings were of European descent. The age range of the siblings was 7 to 23 years with the mean age of 14 years. The age range for their siblings with CCN ($n=12$) was 7 to 17 years with a mean age of 12 years. The CCN of the children varied, as did their diagnoses with three diagnosed with developmental disabilities, three with cerebral palsy, three with congenital disorders, two with genetic disorders and one with chronic lung disease.

Data collection procedures

The siblings took part in face-to-face, individual, semi-structured interviews. The interviews were conducted by two research assistants, trained and supervised by the first author, who is an expert qualitative researcher. While an interview guide was used, the interview adopted a flexible approach in order to be responsive to issues considered important to the siblings or areas previously not anticipated by the research team. Examples of questions asked of siblings included how they defined participation, the types of activities that they participated in, and what it meant to them to participate in those activities. While the goal was to involve each sibling in two interview sessions, nine siblings were not able to commit to two interviews because of scheduling difficulties.

All 16 siblings also drew an ecomap during the first interview session. Ecomaps were used to create a visual representation of the social relationships and networks between places, activities and individuals in each sibling's life (Rempel *et al.*, 2007). Within each ecomap, siblings drew a circle to represent themselves and added additional circles on

the map to construct the network of family and social relations around them. They could indicate on the map, through the use of lines and circles, the types of relationships and the degrees of connection between the places, activities and individuals that they drew on the map (e.g. a thicker line meant a stronger connection).

Siblings who agreed to take part in two interviews were asked to take part in the photovoice method. Photovoice is a participatory research method utilized to address complex issues or events through photographing and discussing a set of images (Wang & Burris, 1997; Wang & Redwood-Jones, 2001). After the first interview, the photovoice method was explained to those five siblings agreeing to take part. Siblings were given digital cameras and asked to take photographs of objects, people, places, or events that represented their everyday life, including the activities that they participated in. The photographs were intended to depict their ideas of participation including activities, places and individuals they engaged with regularly. In the second interview, siblings were asked to talk about their photographs by means of the SHOWeD method (Strack *et al.*, 2004; Dahan *et al.*, 2007), where siblings were led through their series of images, asked to describe what they felt was happening in each photograph and to explain how it related to their lives.

All interviews were conducted in the siblings' homes. Each interview lasted from 30 to 60 min. All interviews were digitally recorded and transcribed verbatim. Field notes were recorded to describe the interview context.

Data analysis

Data analysis involved several stages that included establishing and monitoring patterns in the data, examining relationships between the patterns and creating themes amongst those relationships (LeCompte & Schensul, 1999; Roper & Shapira, 2000). Interview data and field notes were first reviewed repeatedly for significant statements in an attempt to understand siblings' participation experiences and the meanings assigned to their experiences. Attention was given to exploring similarities and differences between participants. The visual data (i.e. ecomaps and photographs) helped to inform the themes emerging from the textual data and contributed to a greater understanding of the siblings' experiences. The visual data was read by probing the context and meanings of the siblings' ecomaps and photographs through the accounts provided by the siblings in their interviews. To enhance the methodological rigour of the study, several measures including careful line-by-line analysis of the transcripts and detailed memo writing were applied (Lincoln & Guba, 1985).

Ethical considerations

The study received ethical approval from the Education/Nursing Research Ethics Board at the researchers' university and adhered to the tenets of the Declaration of Helsinki. For sibling participants under 18 years of age, written consent was obtained from their parents and assent from the siblings. Written consent was obtained from those siblings 18 years and older. All siblings received a modest honorarium for their participation in the study.

Results

Four main themes representing the siblings' perspectives and experiences of participation were identified: (1) participation is about being part of a group; (2) it feels good; (3) I love my sibling but...; and (4) promoting participation.

Participation is about being part of a group

The definition of participation varied between the siblings; however, the central meaning was that it was equated with being a part of something or being involved in a group. Participation was associated with not only 'doing something' or being engaged in an activity, but doing the activity as a member of a group or community as opposed to doing the activity by oneself. Participants viewed participation for their siblings with CCN in the same manner. One sibling expressed as follows:

I think for him (brother diagnosed with autism) too, participation for him is to be a part of something. I think it means for him that he like belongs essentially. (Female, 17 years)

For the siblings participation involved not only taking part in an activity as part of a group, but helping out and making a contribution to the group. It meant being truly engaged with an activity and doing it mindfully. As one sibling stated as follows:

For me it (participation) corresponds with the word "group." I think probably like hockey teams and stuff like... that to participate is to contribute to the team and stuff like that. (Male, 16 yrs.)

Being with my family

When it came to participation, one group that was very important for the siblings to feel a part of, and to spend time with, was the family. Siblings talked about their favourite family

activities, including gatherings, traditions and celebrations. One sibling described the family's Sunday tradition as follows:

Mom takes me and my brother out on Sundays right after our church and there's an ice cream place down there. And my dad comes and brings "N" (sister with CCN) after church and meets me at the ice cream place... (Male, 9 yrs.)

A particularly valued aspect of being with family was spending time with their brother or sister with CCN. Participants recalled engaging in a variety of activities that were enjoyed by their sibling, and where their sibling with CCN could also participate. One sibling stated as follows:

Uh, well we play lots of video games together. Uh, you know, we go out, we had a bike built by "N" (medical supply store that custom-builds mobility devices for individuals with disabilities), so we're doing that for a bit. He likes to see movies, you know, so we go out to see a movie. (Male, 23 yrs.)

Siblings felt special because they were the brother or sister of a child with CCN. They shared many close moments and interactions with their sibling with CCN. There was clearly a bond present between the siblings that did not necessarily exist between the children and parents. As one sibling explained as follows:

But if I come down earlier, then my parents are getting "N" (sister with CCN) ready for school and so I see her for a bit before she gets whisked away... So I always say "hello" and, you know, "have a good day at school"... And so I was putting on her shoes with Mom, but "N" just lifts up her foot for me and I'm like, "ha!" I'm always doing that, rubbing it in my mom's face! (Female, 13 yrs.)

As part of their participation, siblings recognized that they had unique responsibilities to assume in the care of their brother or sister with CCN. This was described by one sibling as follows:

I think we need to look out for our younger siblings more. We have more responsibilities because Mom and Dad count on us. I think Mom and Dad expect more out of us because we're the oldest and we don't have disabilities. (Male, 13 yrs.)

Like their parents (Authors' Reference), part of participating in the care of their siblings involved watching over and

protecting them, including a sense of responsibility to ensure inclusion of their sibling, as illustrated by the following comments:

If anybody like hurts her in school she just lets me know and I'll go and track them down. She just rolls her eyes at me, but I don't like when people do that... So I'm like, "Well she's a person, she shouldn't be excluded, like you wouldn't do that to another kid that was like me. So why do that to my sister?" (Female, 13 yrs.)

When spending time with their brother or sister with CCN, it was also important for siblings to assume a teaching role, as evident in this interview excerpt as follows:

Well, I like going swimming with "C" (brother with CCN) because he's a really good swimmer. He can't do everything, and I like to teach him how to do stuff like dives and stuff. (Male, 13 yrs.)

Being with friends

While siblings valued their family time, participation outside the home was important. It was viewed as a time out from all the responsibilities associated with being a member of a family. One sibling stated as follows:

Um, I also like getting together with my friends because it sort of gives you a break from them... (Female, 11 yrs.)

Siblings spoke of a variety of activities that they enjoyed participating in with their friends, from going to the movies to participating in physical activity (e.g. playing hockey, going for long runs with friends). They revealed that participation with friends helped to build stronger connections between their friends and helped them to feel more a part of their community.

It feels good!

The reasons for participating were tied to the way the siblings felt when they engaged with and belonged to a group where there was a social connection. Throughout the siblings' narratives, comments such as 'It feels good' or 'I just feel happy' were voiced when asked why they valued participation.

In contrast to this sense of feeling good, siblings expressed feeling stressed-out when having difficulties engaging and participating with others. Not belonging to a group also affected how the siblings viewed themselves. The idea of being

invisible or discarded when 'feeling unwanted' was evident in the interviews, as illustrated in this excerpt as follows:

But this year I felt excluded 'cause I didn't make it on any teams this year...Kind of feel like you're unwanted. (Male, 16 yrs.)

While for the most part siblings chose to take part in a group or activity because they enjoyed it, there were times when participation was not always a choice. At times, siblings felt compelled, or that it was their duty, to participate. This was evident particularly in activities having to do with care of the child with CCN. But even in those instances, siblings saw benefits. In fact, siblings also described how having experience with their family member with CCN brought forth opportunities that may not have been available otherwise. One sibling described her experience of being given the opportunity to work with children with special needs as follows:

I just emailed her and talked to the person in charge and said that'd be interesting, and that I wanted to do work with special needs kids. And it's like one-on-one with kids and stuff like that, and I'd thought that it'd be -- that's really cool so... Yes, so I think obviously, like going for the job as like an instructor working with special needs, like I think that's huge. I think I wouldn't be able to be patient with the kids without having a brother with special needs. I wouldn't have a good understanding, right. (Female, 17 yrs.)

I love my sibling but...

Siblings talked about some challenges to participation that included the absence of friends taking part in the activity and lack of time and finances. For example, one sibling stated as follows:... if "K" (sibling with CCN) was able to do like things like play hockey, or something like that, there definitely wouldn't be money available for me to do those and other opportunities. (Female, 18 yrs.)

Although some siblings were hesitant to speak of it, they revealed how being a sibling of a child with CCN affected their participation. Despite the love they had for their brother or sister with CCN, the participants shared feelings of frustration and resentment towards their siblings because of missing out on certain activities. Travelling was the most common activity that participants felt they missed out on as reinforced by the following excerpt:

I've never been out of North America and like sometimes I want to see the world, but because of "N" (child with CCN), we can't really travel. So, sometimes I just feel frustrated that, because I'm always like, "Well why can't we go out there?"... Like, well, we have to change "N" and stuff like that and it all revolves around "N". (Female, 13 yrs.)

Some outings with their family were avoided to be sure that the child with CCN was safe and comfortable.

Even when siblings and their families did participate in certain family activities outside their homes, extra planning was needed to ensure the safety of the child with CCN. One sibling stated:

It's just one of those things that we're going to bring his equipment and stuff, and he's going to walk. We have to really plan out when we go there. When we go, is he going to be able to sit down? ... But uh with "S" (sibling with CCN), we just have to really plan, you know, how are we going to get there? (Male, 23 yrs.)

Siblings explained that if proper supports are not in place, family participation will be negatively affected, as reflected in this sibling's comments as follows:

You [have] got to make sure you have everything in place because if you forget something you're screwed, you know what I mean? If you forget something then we will turn around and go home to get it. (Male, 23 yrs.)

Siblings' participation within their own home was also influenced by their brother or sister with CCN as reinforced by the following excerpt:

...usually my parents kind of figure out like, or we'll have to be upstairs if he's downstairs, or would be downstairs if he's upstairs kind of thing. Or outside if he's sleeping or something like that – or just kind of keep our distance so he just doesn't get upset with all the people. (Female, 18 yrs.)

Taking part in activities with friends on their own was also influenced by being in a family of a child with CCN. Siblings in this study expressed that a lack of respite or babysitting for the child with CCN made it difficult to leave the home to participate in other activities. Siblings described instances where they felt they were missing out on such activities, as the excerpt in the following illustrates:

My grandma has offered to take me, but there's not a lot of time anymore either. 'Cause, it is either a good day for "C" (Child with CCN) or a bad day. And you can tell when he wakes up whether it's one of those days. And usually on those days I help to clean up and stuff like that... So you can't do everything you want to do. (Female, 11 yrs.)

Siblings also described how their future plans and activities were influenced by having a brother or sister with CCN. One sibling stated as follows:

When I was thinking of a university I was going to, I was kind of thinking of maybe like outside my province or something like that. And I remembered I brought something up like that to my mom and she didn't like the idea... One reason was the money...another reason would probably be because there'd be one less person to take care of "K" (sibling with CCN). (Female, 18 yrs.)

Promoting participation

Participants were eager to share advice when asked how participation for siblings of children with CCN could be enhanced. However, as a member of a family who had the experience of living with a child with CCN, the siblings provided recommendations that they felt would help them as well as their family members to participate. Participants first advised that it was important that they and their siblings with CCN take the opportunity to expose themselves to new and different activities. One sibling noted as follows:

You just got to try things and find what works...Um, you definitely got to put yourself out there, like there's some people like "K" (brother with CCN), "K" more so. I think "K" would be a good example who doesn't really do anything, really. He doesn't really do any activities outside of school. Um, he's making progress. He joined the improv (Improvisational) team at school and uh, he's looking to get a job and stuff like that, but yeah, you just got to, I don't know, I think you got to apply yourself. You definitely can't shun everything and then be depressed about not being involved. (Male, 16 yrs.)

Siblings identified ways in which they felt that parents could better promote the participation of their children. Having supportive parents was essential to promoting their participation, as illustrated in this interview excerpt as follows:

Support! My parents are very supportive with me... Everything I do they are, they're always there for me. They're always, they help me out if I need some like advice or something or, um, I don't know. My mom always comes watch me and she'll always give me tips in telling me what she saw and what I can improve on. (Male, 16 yrs.)

Awareness, whether directed at siblings or their family, was seen as an important condition for promoting participation. Siblings felt it would be beneficial if they and their families were informed about programs and activities available for their family's unique needs and felt that this knowledge would aid them and their family to participate. One sibling stated as follows:

Yeah, let them know that it's possible that you can be part of that activity. Um, 'cause we don't really see like people advertising that it's possible for disability people to be doing certain things. (Female, 18 yrs.)

Furthermore, if programs available for children with CCN were more heavily funded, the siblings believed there would not only be more activities, but also advertisements for these programs would increase, thus promoting their awareness.

Nearly all the siblings interviewed told stories about reactions of others when out of the home with their brother or sister with CCN. Consequently, siblings identified educating and informing others in the community about multiple complex needs with the goal of building understanding as important for participation. They hoped that with more understanding from others in the community, they and their families would feel more comfortable participating in activities out of the home as a family and experience an increased sense of inclusion. One sibling commented as follows:

But I think that people should be more educated and not just family members, but like general public should be more. Because like sometimes we go out and it's just like, yeah, people stare. (Male, 23 yrs.)

Participants recognized that it was important for their parents to take time to relax and participate in what interested them. The siblings felt by doing so, there would be less stress in the home, and hence, they would feel more relaxed and comfortable in doing things that they normally would do. This is illustrated well in the excerpt that follows:

I think they (parents) should take time for themselves not only because is it good for parents to take time for yourself,

to relax yourself, but also like for the people around you 'cause I think that, like obviously, any one family affects them... Because you're around them all the time. So, if I'm around a stressful person, like if my mom's stressed, that's going to affect me more than she realizes – not only her, but it affects me 'cause it stresses me out. Does that make sense? It is contagious, so just take time for yourself. (Female, 17 yrs.)

Discussion

Although siblings in the study had varying definitions, many understood participation as 'doing something'. However, participation was more than just doing, and included both being engaged in an activity and being accepted as a part of a group. 'Being' rather than simply 'doing' was discussed by family of CCN, specifically parents (Authors' paper). This aspect of participation remains relevant in reference to sibling experiences.

While participation involved a variety of activities and individuals, it always remained focused on family relations and their sibling with CCN. Most importantly, this study revealed that the sibling relationship was a priority. The close ties between siblings and their brothers and sisters with CCN reinforced to siblings in our study that they were special and had a distinctive role in the life of the child with CCN. Involvement in receiving comfort from their sibling or being able to do things for their sibling demonstrated the strength and importance of the sibling relationship. Siblings even took on protective and teacher roles. Previous research has shown that siblings have an increased desire to maintain a sense of presence by 'being there' for their ill sibling (Woodgate, 2006). Research has also revealed that siblings may find themselves adopting parental roles as an attempt to make as few demands as possible on parents and as an acceptance of their family situation (Barr & McLeod, 2010; Burke, 2010; Lapwood & Goldman, 2012). As well, siblings along with their parents worked together to accommodate and provide care for the child with CCN despite moments of conflict and strife, showing an increased cohesion also found by Prchal and Landolt (2012).

There were a number of reasons why siblings participated, and mostly siblings saw these reasons positively and as resulting from choice. Participating helped siblings to feel good, or enjoy their passion for an activity, such as a sport. This also reflects the desire for social contact and belonging to a group. Spending time with peers and talking with them about the illness they encounter at home helps siblings to

deal better with the illness by giving them hope and relieving them of worry (Prchal & Landolt, 2012). The type of group was also important, in terms of being a group they wanted to participate in. However, in some cases participating was more tied to a duty to participate and assist their family or sibling to the point where, at times, siblings felt compelled to participate to ease the burden on their families.

Despite some hesitation, siblings also spoke of the challenges to participation including lack of time or finances to be able to participate in certain activities. More importantly, participation was influenced by requirements for caring for the child with CCN with an increased need for time and resources focused on the child with CCN. Specifically, families with children with CCN must spend considerable time adapting to their needs (Axelsson *et al.*, 2013). Activities that might cause upset or overstimulation were commonly avoided, including entering spaces with many people or attending events with loud noises or music. In other studies, siblings of children with chronic pain described not being able to travel or go on vacation in relation to their sibling's limitations (Gorodzinsky *et al.*, 2013). Major issues when leaving the habitual space in the home were mainly organizational (e.g. obtaining support or equipment, preparing required devices and accessing unfamiliar spaces). Even so, siblings discussed that outbursts could still happen, which would make participating more difficult in terms of contingency planning. Short-stay respite programs for children living with physical impairment show benefit for families, especially in terms of allowing siblings opportunity to spend time with their parents alone (Swallow *et al.*, 2012).

Despite a strong sense of love, siblings found it difficult when their family avoided activities to maintain safety and comfort. The emotional impact of living with a child with CCN can have lasting effects on siblings' lives, including academic achievements and career outcomes, and lingering feelings of guilt and a perceived need to take on the problems of others seen to be at a disadvantage (Caplan, 2011). Feelings of this nature may result in manifestation of behaviours seen with sibling rivalry. At times, not participating with other family members in activities at home produced feelings of exclusion related to 'not being a part' of the group. Feelings of exclusion and neglect, regardless of whether they are unintentional, may manifest as feelings of isolation; situations of this type may put siblings at risk of developing difficulties in adjustment and functioning (Burke, 2004; Goeke & Ritchey, 2011; Lapwood & Goldman, 2012).

Siblings in our study provided specific recommendations for professionals and/or clinicians that may help families caring for CCN towards increased participation. To promote participation, most siblings recommended effective awareness, whether directed to others or to them and their family, as an important condition to promoting participation (i.e. communication and information). Greater awareness of promoting participation at differing levels of ability and educating community members to build understanding, can help families know that there are opportunities to participate in a supportive and accepting manner.

Siblings also recognized that parental stress influenced their participation, and hence felt it was important for their parents to relax and participate in things that interest them. Ensuring that parents of children with CCN have adequate services and supports to deal with the physical, psychological, social and financial challenges of parenting children with CCN (Carnevale *et al.*, 2008) will help to decrease the 'contagious' nature of stress, leading to improvements in the home environment.

Limitations

Our study involved siblings of children with varied CCN; therefore, future research focused on siblings of children with specific CCN is warranted. All sibling participants were of European descent, and thus, exploring the perspectives of those with different ethnic backgrounds would be of value. Accessing service providers and professionals from social, health and education systems would add context to siblings' experiences. Finally, the wide age range precluded an understanding of the differences and similarities in participation experiences between younger and older siblings, especially considering the sample size was small.

Conclusion

Siblings prioritized the relationship with their sister or brothers with CCN in their life and a great deal of their participation was chosen with their sibling in mind. Sibling-to-sibling relationships were distinct and meaningful and, as a result, participation was always done mindfully and with the family needs at the forefront. Indeed, as the *Convention on the Rights of Persons with Disabilities* attests, persons with disabilities, as well as their family members, should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of their rights (UN General Assembly, 2007).

Key messages

- While participation for siblings involved a variety of activities and individuals, the central meaning of participation for siblings of children with complex care needs (CCN) was that it was equated with being a part of social experience or being involved in a group.
- A primary focus of participation was on feeling part of a family, with siblings prioritizing the relationship with their sisters and brothers with CCN in their life; a great deal of their participation was chosen with their sibling in mind.
- Despite the love they had for their brother or sister with CCN, siblings acknowledged that the presence of a child with CCN in their families had an impact on their ability to participate, as did other factors, including time and finances.
- Siblings indicated that important conditions to promoting participation in siblings of children with CCN included a willingness to expose oneself to new activities, parental support, and public education about children with complex needs.
- Future research studies are needed from the perspective of service providers and professionals to provide context to the experiences of siblings of children with CCN.

Conflict of interests

The authors declare there are no conflicts of interest associated with this manuscript.

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