Received: 17 April 2023 | Revised: 18 December 2023 | Accepted: 5 February 2024
DOI: 10.1111/cch.13241

RESEARCH ARTICLE

WILEY

Being a sibling of a youth with a neurodisability: A qualitative study about the roles and responsibilities during the transition to adulthood

Linda Nguyen[1,2,3] | Susan M. Jack[4,5,6] | Hanae Davis[7] | Samantha Bellefeuille[7] | Dana Arafeh[7] | Briano Di Rezze[2,3] | Marjolijn Ketelaar[3,8] | Jan Willem Gorter[2,3,8,9]

[1]School of Physical and Occupational Therapy, Faculty of Medicine and Health Sciences, McGill University, Montreal, Quebec, Canada

[2]School of Rehabilitation Science, Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada

[3]CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario, Canada

[4]School of Nursing, Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada

[5]Department of Health Research Methods, Evidence, and Impact, Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada

[6]Offord Centre for Child Studies, Hamilton, Ontario, Canada

[7]Sibling Youth Advisory Council, Hamilton, Ontario, Canada

[8]Centre of Excellence for Rehabilitation Medicine, UMC Utrecht Brain Center, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, The Netherlands

[9]Department of Pediatrics, McMaster University and McMaster Children's Hospital, Hamilton, Ontario, Canada

Correspondence
Linda Nguyen, School of Physical and Occupational Therapy, Faculty of Medicine and Health Sciences, McGill University, Montreal, Quebec, Canada.
Email: linda.nguyen2@mcgill.ca

Funding information
This study was funded by the Canadian Institutes of Health Research Patient-Oriented Research Award – Transition to Leadership

Abstract

Background: During the transition to adulthood, a common challenge that youth with a neurodisability may experience is learning how to navigate services in the adult care system. During this transition youth may rely on their families, including siblings, for support. However, delineation of sibling roles and responsibilities during this transition period are unclear. This study aims to identify the roles and responsibilities that siblings perceive to have with their sibling with a neurodisability during the transition to adulthood, and describe the decision-making process of how siblings chose these roles.

Methods: In this descriptive qualitative case study, siblings were eligible to participate if they were between 14 to 40 years old, had a sibling between 14 to 21 years with a childhood-onset neurodisability and spoke English. Semi-structured interviews augmented by techniques of photo elicitation and relational maps were conducted. Reflexive thematic analysis was applied to identify sibling roles, as well as the emotional and decision-making process associated with these roles. Our team partnered with siblings with lived experience in all study phases.

Results: Nineteen participants (median age = 19 years, range = 14 to 33 years) from 16 unique families were interviewed. Six unique roles were described: friend, role model/mentor, protector, advocate, supporter, or caregiver. The emotions that siblings experienced with each role, also known as emotional responsibility, were categorized into levels of low, medium or high. Siblings also described a four-phase decision-making process for their roles: (1) acquiring knowledge; (2) preparing plans; (3) making adjustments; and (4) seeking support. Intrapersonal characteristics, including personal identity, values and experiences, influenced roles assumed by siblings.

Conclusions: Siblings identified needing support as they process their decisions and emotional responsibility in their roles when their sibling with a neurodisability is transitioning to adulthood. Resources should be developed or further enhanced to support siblings.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.
© 2024 The Authors. *Child: Care, Health and Development* published by John Wiley & Sons Ltd.

Stream - Phase I (TLS-170679) (LN) and the CHILD-BRIGHT Graduate Student Fellowship in Patient-Oriented Research (LN). During the work presented in this article, JWG held the Scotiabank Chair in Child Health Research.

KEYWORDS
disabilities, healthcare transition, qualitative research, roles, siblings, youth

1 | INTRODUCTION

During the transition to adulthood, youth typically identify and focus on goals related to education, employment, leisure and relationships (Stewart, 2009). Strategies to achieve these goals are often initiated during the developmental periods of adolescence and emerging adulthood, during the ages of 12 to 25 years (Sawyer et al., 2018). Youth with a neurodisability, such as autism spectrum disorder or cerebral palsy, may experience challenges during these developmental stages in independently navigating these tasks. Neurodisability can be broadly defined as a group of congenital or acquired long-term conditions that result from an impairment of the brain and/or neuromuscular system that may create functional limitations (Morris et al., 2013). Additionally, youth with a neurodisability typically must also learn how to navigate new environments, including healthcare, education, recreation and social services during the transition to adulthood (Freeman et al., 2018; Zarrett & Eccles, 2006). For youth with neurodisabilities, they will also experience healthcare transition which is defined in the literature as a purposeful and planned process of moving from paediatric-oriented to adult-oriented care services and system (Blum, 2002). Ideally, youth and their families, including siblings when present, are prepared for this transition to adulthood. Siblings have an important role in the family, but their role during the transition phase from adolescence to adulthood. Throughout childhood, typically developing siblings may assume multiple roles in relation to their sibling with a neurodisability such as a mentor, role model or friend (Hall & Rossetti, 2018). Siblings often spend proportionately more time with their sibling with a neurodisability compared to any other family member (Atkin & Tozer, 2014). The birth order between siblings can also affect their role. For example, older siblings could bring their own experiences with transition to adulthood and might be sources of support about social and academic experiences (Hayden et al., 2023; Tucker et al., 2001).

Despite the unique relationship between siblings, many families may not have or may delay formal discussions about the roles and expectations of siblings until after the process of transition (Atkin & Tozer, 2014). This can lead to missed opportunities to be engaged in healthcare and increased anxiety about future roles for siblings. Siblings of individuals with a disability have expressed their concerns about their present and future care responsibilities. A needs assessment survey was conducted Canada in 2018 with siblings ages 20 years and older who had a sibling with an intellectual and/or developmental disability (Redquest et al., 2020). Within the sample, approximately 71% of siblings expected that they would provide increasing caregiving support to their sibling with a disability in the future (Redquest et al., 2020). Siblings often have worries about responsibilities in the future, such as guardianship or financial responsibilities that they might take on when their parents can no longer be the primary caregivers (Arnold et al., 2012).

Siblings may process these different concerns and consider the extent to which they choose to take on certain roles for their siblings with a neurodisability. A review and analysis of online resources found that siblings shared in blogs and interviews about the roles and responsibilities that they have to their sibling with a neurodisability, such as providing support and attending therapy appointments (Nguyen et al., 2021). Siblings also shared information about the emotions they experience when they assume many of these roles, including feelings of frustration, guilt and stress, as well as love and care for their sibling with a neurodisability (Nguyen et al., 2021). While siblings have shared brief descriptions of their roles, details are needed about the types of roles that siblings have to their sibling with a neurodisability during the transition to adulthood. An in-depth understanding about these roles from the perspectives of siblings with lived experiences can help identify the types of resources that are required to support them in their roles.

Key Messages

1. Engaging with siblings with lived experiences as co-researchers was valuable to explore the need for this study, deepen the level of understanding and interpretation of findings and discuss the implications of the findings.
2. Siblings of youth with a neurodisability assume multiple roles over the life course trajectory.
3. Each sibling role is associated with a level of emotional responsibility that balances the personal interests of the sibling with the well-being of the sibling with a neurodisability.
4. Siblings of individuals with a neurodisability require support as they transition into their roles.

2 | OBJECTIVES

The overall aim of the BrothErs and Sisters involvement in health care TranSition for youth wIth Brain-based disabilitieS (BEST SIBS) Study is to understand the experiences of siblings of youth with a neurodisability during the transition to adulthood, including the transition from paediatric to adult healthcare. This paper focuses on the specific objectives to identify and describe (1) the sibling roles and responsibilities across the trajectory to emerging adulthood, including any

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

functions associated with the healthcare transition of their sibling with a neurodisability; (2) the values and emotions that siblings associate with these roles; and (3) the decision-making process of how siblings choose these roles.

3 | METHODS

3.1 | Engagement of siblings with lived experience in the research process

Patient-oriented research is an approach to engage patients and families throughout all phases of research (*Strategy for Patient-Oriented Research - Patient Engagement Framework - CIHR*, 2014). The engagement of patients and their family, including siblings, can help enhance the value and relevance of the research (Canadian Institutes of Health Research, 2019; Forsythe et al., 2019; Manafo et al., 2018). To accomplish this goal, the Sibling Youth Advisory Council (SibYAC) was established in 2018 by the first author (LN) as a research partner to inform all study phases. The SibYAC included six young adult siblings, with five sisters and one brother, between 21 to 28 years old, of youth with a disability. They were recruited through word-of-mouth, for example, through their experiences in previous research studies, projects, or work with the research team. Some SibYAC members would connect with other siblings with lived experience who were interested to partner in research. Conversation tools, including the Involvement Matrix (Smits et al., 2020) and Engagement Tool (Ontario Brain Institute, 2019), were used to guide ongoing discussions with each SibYAC member to understand how they would like to be engaged in each study phase. Since study inception, the SibYAC members have actively engaged in multiple study phases, including (1) preparation, such as co-creating recruitment materials and pilot testing the interview guide; (2) execution, such as recruiting participants by sharing the study information in their networks; and (3) knowledge implementation, such as co-presenting experiences of our partnership at local, national and international conferences. All SibYAC members received compensation for their engagement in our partnership, which was based on a discussion about how they preferred to be compensated as well as the guidelines by the CHILD-BRIGHT Network in Canada (CHILD-BRIGHT Network, 2020; Nguyen et al., 2021; Novak-Pavlic et al., 2023).

In this study, siblings were asked to identify and describe the roles they assume, and the responsibilities attributed to them, within the context of their sibling with a neurodisability transitioning from the paediatric to adult healthcare system. This study was designed as a qualitative single case study (Yin, 2018) and a detailed description of the study methods has been published elsewhere (Nguyen et al., 2021).

3.2 | Study participant recruitment

A purposeful sample of individuals who self-report being a sibling to another individual with a disability were recruited. Siblings were eligible to participate if they (1) were between 14 to 40 years old; (2) have a sibling between 14 to 21 years old with a childhood-onset neurodisability; and (3) spoke English. We sought a purposeful representation of siblings different genders who had siblings with different diagnoses. Recruitment materials, including a poster and video posted on the project website (CanChild Centre for Childhood Disability Research, 2021) were shared on social media platforms (e.g., Facebook, Twitter), the personal networks of the research team and disability-specific organizations such as the CHILD-BRIGHT Network (CHILD-BRIGHT Network, 2019) and Kids Brain Health Network (Kids Brain Health Network, 2021). Study information was also shared with the siblings in families who participated in a randomized controlled trial (Gorter et al., 2021). Snowball sampling was also used, in which study participants could share the study information with other potential siblings who may be interested in participating in this study (Patton, 1990; Robinson, 2014). Participants were recruited from February 2020 to July 2021. Data generation and data analysis occurred concurrently. Participant recruitment was completed when there was a complete description with the dimensions and properties of the sibling-identified roles. In this paper, the term 'sibling participant' will be used instead of 'typically developing sibling' as a participant was not excluded if they had a neurodisability.

3.3 | Ethical approval

This study received ethical approval from the Hamilton Integrated Research Ethics Board (Project #7932). Consent was obtained in a three-step process (Wang & Redwood-Jones, 2001): (1) to participate in the interview; (2) to share photographs, including those from their parents and/or sibling; and (3) to share photographs on specific platforms (e.g., study publication, conference presentations). Steps two and three were optional; participants could choose to participate in the interview without sharing photographs.

3.4 | Data collection

The triangulation of data sources is a hallmark characteristic of case study research. In this study, a comprehensive description of the case was established through generating data from three sources: interviews, photo elicitation, and graphic elicitation of relational maps. Semi-structured, one-on-one single interviews were conducted with participants. These interviews were conducted by the first author (LN), and because of public health measures to reduce the transmission of SARS-Cov-2, were conducted via a web conference platform. To enhance rapport and increase the quality and detail of information shared, two elicitation techniques augmented the in-depth interviews. Using photo elicitation, participants were asked to share three to five photographs that described their sibling experiences, which could be brought to the interview or uploaded before the interview on a secure cloud storage. To understand the context of the family dynamics and the role of the sibling participant within the family, graphic elicitation of relational maps was used where participants were asked to draw a

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

family tree diagram of members in their immediate family at the beginning of the interview. The purpose of these family tree diagrams was to develop rapport with participants and reflect on the different relationships in their immediate family including their sibling(s) and parents. Graphic elicitation tools, such as relational maps, have been reported to be beneficial for recalling and expressing complex thoughts (Copeland & Agosto, 2012). A summary of the interview questions is provided in Table 1.

3.5 | Data analysis

Data generation and data analysis occurred in an iterative process throughout participant recruitment. Interview transcripts, including the verbal descriptions of the photographs and family tree diagrams, were analysed using reflexive thematic analysis (Braun & Clarke, 2006). The first author (LN) wrote field notes after each interview to identify initial codes and categories. A summary of the initial codes, description of the categories, and excerpt quotes from the data were reviewed and discussed among consultants. Summaries of the codes and categories were shared in an iterative process to ensure that there was a comprehensive description of the categories. Consultants were from a range of educational backgrounds in Canada, including cognitive psychology, education, nursing, occupational therapy, physiatry, rehabilitation, user experience design and patient-oriented research. Consultants included the SibYAC and five graduate students who were purposefully identified based on their diverse educational backgrounds and connection with this research team. During data analysis, consultants often had questions about the categories such as whether the roles and responsibilities shared by participants were similar and/or different based on their lived experience or professional background. Further discussions were held to develop a comprehensive description of the categories, such as how the roles and responsibilities of siblings might change over time. Expert consultation was a form of analyst triangulation and peer debriefing to enhance the credibility of the data (Patton, 1999).

TABLE 1 Summary of interview questions.

Questions asked during the graphic elicitation of relational maps
1. To start, can you draw/write about who you are?
2. Who lives at home with you?
3. Are there any family members who do not live at home with you, but you also often talk with or ask questions?
4. Can you draw/write who your siblings are?
5. How old is each of your siblings?
6. What grade is each of your siblings in?
7. Which sibling has a disability? What type of disability does your sibling have?

Questions asked during photo elicitation
1. Can you tell me about this picture?
2. Who is in the picture?
3. Where was this picture taken?
4. Why did you take this picture?
5. What does this picture mean to you?
6. Is there a picture that you wish that you had?

Questions asked to describe sibling relationships
1. How would you describe your sibling relationship?
2. One of your siblings is currently preparing for health care transition. When your sibling turns 18 years old, they will have to transfer from paediatric to adult care. Have you heard about this before?
3. As you grow up, how do you see the future of you and your siblings as adults?
4. As a sibling to another sibling with a neurodisability in your family, what is the most important information about your personal experiences that would be most important for other people, including health care professionals to understand?

3.5.1 | Reflexivity

The first author (LN) is an academic scholar (PhD in Rehabilitation Science) with a focus on childhood disability. She was responsible for conducting the interviews and coding the transcripts. She has experience conducting qualitative research to understand the perspectives of parents of children and youth with a disability. From her personal experiences, she recognizes the value of multigenerational families where each member has a role in the family. She understands and acknowledges the importance of a collectivist culture to care for the family, alongside individualistic values from the Western culture in Canada. During the process of conducting and coding the interviews, she continuously wrote reflexive memos to acknowledge how her academic and personal experiences influenced how she collected and analysed the data.

3.5.2 | Conceptual framework

The application of a conceptual framework is necessary in a qualitative study and congruent with reflexive thematic analysis (Baxter & Jack, 2008; Braun & Clarke, 2019). The use of a conceptual framework ensured that there were boundaries about the case of sibling participants with a clear focus for data analysis (Baxter & Jack, 2008) Two theories were used to develop the initial conceptual framework:

1. *Transition theory* (Meleis et al., 2000): Meleis and colleagues developed this theory to describe the different types of transitions, properties of transition, and outcomes experienced by individuals during the process of transition.
2. *Bioecological systems theory* (Bronfenbrenner, 1992): Urie Bronfenbrenner developed this theory to describe person-environment transactions. The analysis for this paper focused on the microsystem, which is comprised of individuals in the immediate family environment of the sibling, including the sibling with a neurodisability, siblings and parents.

The propositions, or statements of how concepts relate to each other based on empirical findings from the literature, in the initial conceptual framework provided guidance about the factors to analyse

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

that could influence the relationship and roles that sibling participants have with their sibling with a neurodisability. The factors analysed included gender, age and health of the sibling participant and sibling with a neurodisability.

4 | RESULTS

Nineteen sibling participants with a median age of 19 years (range = 14–33 years) from 16 unique families were included. Fourteen participants described their relationship to one sibling with a neurodisability and five participants described their relationship to two siblings with a neurodisability, for a total of 20 unique siblings with a neurodisability (median age = 17 years, range = 14–21 years) during the interviews. Three participants disclosed that they had a neurodisability. Table 2 describes the characteristics of the siblings and families. Interviews ranged from 45 to 104 min.

4.1 | Roles

Sibling participants described six unique roles they assumed in relation to supporting their sibling with a neurodisability: friend, role model/mentor, protector, advocate, supporter, or caregiver (Figure 1). These roles differed across the trajectory to emerging adulthood and the degree of emotional responsibility invested by the sibling in their roles varied. Detailed descriptions about each role are provided in Table 3.

Different levels (low, medium or high) of emotional responsibility, or the accountability that an individual has for specific emotions, were associated with each role (Figure 1) (McCormick & Schleifer, 2020; Sankowski, 1977). While individuals are responsible for the emotions that they feel, these emotions represent their state of mind (McCormick & Schleifer, 2020). Sibling participants described how they learned to control these emotions in order to best assume their role to their sibling with a neurodisability. During a sibling's life course, one of the first roles assumed as a child was that of a friend. Siblings described playing with their sibling with a neurodisability as having a low level of emotional responsibility. They could simply play with their sibling with a neurodisability as they would with their other siblings or peers.

During adolescence, sibling participants began to take on the roles of being a role model/mentor, protector, advocate or supporter, which carried a medium level of emotional responsibility. Siblings felt that they had to be present for their sibling with a neurodisability by offering guidance, yet they also wanted to prevent their sibling with a neurodisability from feeling negative emotions. In the role of a protector or advocate, for example, participants described situations where they remained positive in front of their sibling with a neurodisability, but they also had to explain the neurodisability to others who might not understand such as their peers or other family members. A sibling participant described how he advocated for the needs of his sibling:

TABLE 2 Demographics of sibling participants.

Characteristics	Total (*N* = 19)
Gender of sibling participants	
Female	12
Male	7
Gender of sibling with a neurodisability	
Female	5
Male	15
Type of neurodisability of the sibling	
Autism spectrum disorder	12
Cerebral palsy	4
Hereditary spastic paraplegia	1
Intellectual disability	1
Attention deficit hyperactivity disorder	1
Epilepsy	1
Sibling dyad (sibling participant-sibling with a neurodisability)	
Sister–brother	11
Sister–sister	3
Brother–sister	4
Brother–brother	6
Birth order (sibling participants to their sibling with a neurodisability)	
Older sister, brother	7
Older sister, sister	3
Older brother, sister	4
Older brother, brother	2
Younger sister, brother	4
Younger sister, sister	0
Younger brother, sister	0
Younger brother, brother	4
Number of siblings with a neurodisability in the family	
1 sibling with a neurodisability	15
2+ siblings with a neurodisability	4
Total number of siblings in the family	
2 siblings	8
3 siblings	6
4+ siblings	5

> ‘My mom and dad are not so understanding of her at times so it's, it's why I like to protect her in that way and just reminding my parents that she struggles with some of the exact same things that I do’
>
> (Older brother of a sister with autism spectrum disorder).

Overall, sibling participants wanted to be supportive of their sibling with a neurodisability, and processed how they could provide the most optimal support and guidance.

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

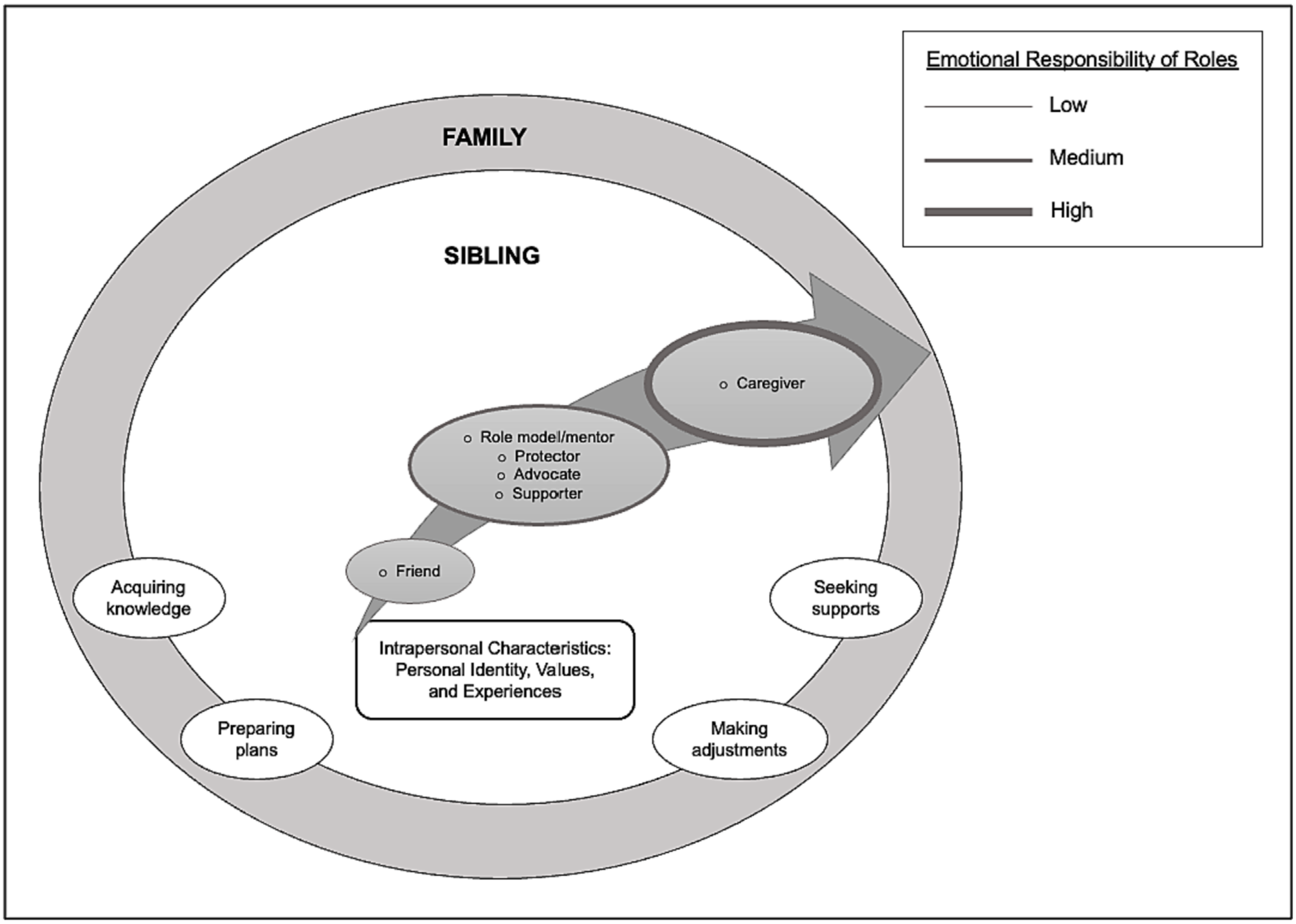

FIGURE 1 The internal process of factors that influenced the roles that sibling participants had to their sibling with a neurodisability.

As sibling participants entered emerging adulthood, some described that they were either preparing for or had assumed the role as a caregiver. This role had the highest level of emotional responsibility, because sibling participants needed to ensure that the basic needs of their sibling with a neurodisability were met such as assistance with therapy and personal hygiene. This caregiving role also included learning about managing the health of their sibling with a neurodisability, for example, driving them and attending healthcare appointments. A sibling participant described how she was actively involved in the healthcare transition process by taking notes and debriefing with their parent after the healthcare appointment. Some sibling participants gradually took on these caregiving tasks as they perceived this role to be an implicit expectation within their family, whereas other sibling participants actively chose to have these tasks. Many sibling participants described that while they knew about the general services that their sibling with a neurodisability was receiving, they wanted to be more actively involved and aware about process of transition to adulthood for their sibling with a neurodisability. This transition to adulthood included understanding the services that would be available to their sibling with a neurodisability in healthcare and employment. Sibling participants felt multiple emotions, such as guilt, as they were processing how they could continue with caregiving tasks while balancing their own needs with respect to maintaining employment or completing post-secondary education. A sibling participant described how she often had to be aware of when she was looking after her sibling with a neurodisability:

> ‘Whereas like you're always watching out for her, your mind is always on and like watching for danger and making sure she's okay and don't mess this up. I still have to have my mom brain on or like my caregiver brain on.’
>
> (Older sister of a sibling with hereditary spastic paraplegia).

The dynamic balance of emotions in the role of a caregiver carried a high level of emotional responsibility.

4.2 | Intrapersonal characteristics

Siblings perceived that certain intrapersonal characteristics, including their personal identity, values and experiences, influenced their adoption of different roles.

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 Description of roles.

Role	Description	Illustrative Quotes
1. Caregiver	To care for the sibling with a neurodisability to carry out activities of daily living, such as daily hygiene and making food, while also making sure that the sibling continues with their routine schedule including going to school.	'I help him with his homework when I can. General hygiene, like brushing his teeth, taking him to the bathroom, showering, getting food, water, setting up his iPad so that he can play games'. (Sister of a brother with cerebral palsy). 'Sometimes I feel like his mini-parent, but not his parent. But I do, I've been protective of him since we were younger'. (Older sister of a brother with autism spectrum disorder). 'I've always been more of a caregiver… so in elementary school, we would go to school together. I would take the special transportation bus with her and I would bring her to class in the morning and then go to my class. And then after school, I would go get her and walk with her'. (Older sister of a sister with a physical disability).
2. Role model/ mentor	To complete activities related to school, such as tutoring, but to also provide mentorship in life such as making friends and new relationships.	'Yeah I do a lot of tutoring "cause I tutor my cousins. I help my brother. And then I work at a tutoring centre"'. (Older sister of a brother with an intellectual disability). 'Even with just like friends. He's like, like "how do I kind of like figure that whole thing out?" Like how do I like ask someone like "oh like let's go hang out" like "cause so I've kind of like, it shifted like as of like, I'm your big sister, I'm kind of more like a friend and like I've been through all of this so like I can help you with that kind of thing"'. (Older sister of a brother with autism spectrum disorder).
3. Protector	To provide a sense of security.	'All the things that were happening at school around them that I've noticed or like, you know, people teasing them, and you know, I tried my best to stick up for them and I would say something, but you know, because I was so small (laughter) and because I was so much younger, no one really at school took it seriously'. (Younger sister of two older brothers with autism spectrum disorder).
4. Advocate	To provide information to explain to individuals, such as other family members, about disability. To begin to speak up about the importance of supports for their siblings with a neurodisability.	'To me, it's, it's quite spontaneous, quite natural. It's not something that I just plan to do. It, it just strikes up into conversation, so like it, it's quite natural. Or if my grandparents just like question about it, then, like if my grandparents just ask "what's going on?" and stuff like that, then it's just natural to me. It's nothing like uh, there's nothing planned ahead'. (Older brother of a brother with autism spectrum disorder). 'Yeah, there is like, um, like a thing to sign up for, for talks with MPP with increasing public health funding. So um, so hopefully they'll do a related topic to my brother for this semester'. (Older sister of a brother with autism spectrum disorder).
5. Supporter	To provide emotional support, such as being there for the sibling with a neurodisability when they are feeling overwhelmed or experiencing challenges. In some situations, this role would also involve supporting the sibling with a neurodisability in explaining information to parents and caregivers.	'Whenever she comes to me, it's more like emotional, so I would give her a hug or something. Let her know that I'm there'. (Older brother of a sister with autism spectrum disorder). 'I guess, he's, um, he gets discouraged very easily and sometimes overwhelmed, um, when he thinks that he can't succeed. So kind of always reminding him that, "You know what, as long as you've done your best then um, like you've- you've given it your all so like you should be proud about that"'. (Older sister of a brother with autism spectrum disorder). 'I do things like, um, you know, [name of second oldest brother] and I, like I'll show him or I'll help him like look for something, even if it's just something simple like [name of second oldest brother] is saying, like, "Oh I want to tell Mom and Dad that" you know, I'm going to say this as an example like "I want to ask this for Christmas, can you- can you help me look for it"'. (Younger sister of a brother with autism spectrum disorder).

(Continues)

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 (Continued)

Role	Description	Illustrative Quotes
6. Friend	To have fun, have conversations and do activities together.	'We would really like to do things together and just have fun together and laugh. And he wants to have adventures. When we were little, we would build forts together and hang in the forts or like, just planning to do whatever outside with the neighbourhood kids'. (Older sister of a brother with autism spectrum disorder). 'At school, we'd be together, like at recesses or lunch time'. (Younger sister of two brothers with cerebral palsy).

4.2.1 | Personal identity

In this study, reference to a participant's 'personal identity' took into account their reflections on how their gender, age and birth order in the family influenced the roles they assumed. When participants were older than their sibling(s), they most typically described assuming caregiver, role model, or mentor roles. Older sibling participants also described being a protector, for example, to physically protect their sibling with a neurodisability from bullying or emotionally protect them from feeling negative emotions by not oversharing their own personal conflicts and stresses.

Gender further influenced the types of roles that sibling participants had. Twelve participants identified as females, and many of them chose or were expected to have caregiving responsibilities. Some participants felt an implicit expectation from their parents to assist with activities of daily living, such as personal hygiene or preparing meals, for the sibling with a neurodisability. It was evident across participants that the number of responsibilities they assumed with respect to the care of their sibling increased as they got older; most typically their care responsibilities included staying at home with their sibling when their parents were out, and then expanding as they aged to include activities such as picking up their sibling from school or assisting with the delivery of different forms of therapy. Many sisters felt the need to become guardians to their sibling with a neurodisability regardless of their age, as one sister described:

> 'I have been starting to think about it [the future]. My parents are gonna get old and then I might be on my own. I know that I have to take over what they were doing, so booking all their appointments and understanding what their needs are. I know that it's going to be up to me to make sure that they're getting everything that they [brothers with autism spectrum disorder] need'
>
> (Younger sister of brothers with autism spectrum disorder).

Sibling participants, especially sisters, often thought about the future and how they could provide caregiving support to their siblings with a neurodisability. In this study, most brothers also cared for their siblings with a neurodisability; however, in contrast to female participants, they more likely to assume a friend or supporter role such as comforting their sibling with a neurodisability during family conflicts.

4.2.2 | Value of familial responsibility

The value of familial responsibility was identified by many sibling participants as being important, which influenced their roles. For example, an older sister described how her value of familial responsibility were instilled by her parents:

> So it's like they've always encouraged us to kind of bond with each other, like spend time with each other. Even with me going off into university, like making sure that we still remain in contact because… as my parents grow older, I don't know when they're going to move on so… it has to be like me and my brother kind of navigating life together.
>
> (Older sister of a brother with autism spectrum disorder).

Although some sibling participants did not mention how they came to adopt this family value, many sibling participants felt this familial responsibility, in which they were expected to take care of their sibling with a neurodisability.

4.2.3 | Experiences

Among some sibling participants, their values were influenced by personal experiences. Some sibling participants shared that their own experience of having the same neurodisability as their sibling meant that they could understand the challenges that their sibling was experiencing. For example, some sibling participants did not have a good experience with certain medications or tried different types of therapy. Based on these personal reflections, sibling participants wanted to share their experiences about how they overcame certain challenges to manage their neurodisability with their sibling with a neurodisability. They wanted to support their sibling with a neurodisability through similar challenges that they faced and overcame. Overall, sibling participants who shared experiences of having the same neurodisability as their sibling perceived that they were in a stronger position to be a mentor and offer guidance.

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

4.3 | Decision-making process

As sibling participants reflected on their experiences as both they and their sibling aged, they described a distinct decision-making process of how they determined the roles and responsibilities they would assume. This four-phase process consisted of (1) acquiring knowledge; (2) preparing plans; (3) making adjustments; and (4) seeking support.

4.3.1 | Acquiring knowledge

Sibling participants identified that they needed to acquire knowledge about how they can best support their sibling with a neurodisability. Often, they turned to their parents for knowledge about the neurodisability. When they first learned about the diagnosis, which was usually through conversations with their parents, they had questions about the diagnosis and what the diagnosis meant for their roles as siblings. The types of questions that sibling participants asked depended on their age. If they learned about the diagnosis as young children, they required explanations about what the diagnosis looked like. In some families, the siblings received their diagnosis of having a neurodisability during adolescence. Siblings who were adolescents or young adults had more specific questions about how the diagnosis of their siblings might affect their life. An older brother described the questions that he asked when he first learned about the diagnosis of his sister:

> How will my day-to-day life need to change so that I can like help and make sure things go smoothly with her? I think those were probably my first questions…. “What just happened?”… “What will we need to do now just to make it easier for everyone and… just a smooth transition to her new way of life”
>
> (Older brother of a sister with epilepsy).

For all sibling participants, they wanted to have sufficient knowledge about how they can best support their sibling with a neurodisability.

4.3.2 | Preparing plans

Sibling participants described how they needed to prepare plans, which included how they coordinated plans with other siblings and members in the family. For example, they needed to make plans with their friends and family if they had to stay at home to take care of their sibling with a neurodisability. A sister described her feelings when she was not able to socialize with her friends due to her responsibility with her brother:

> They [friends] will invite me out… but you know, sometimes I'll have to refuse because I can't be away from home that day… I think it's hard for them to understand no matter how hard I try to explain it to them that my role at home is important.
>
> (Older sister of a brother with cerebral palsy).

Families needed to prepare for the transition to adulthood of the sibling with a neurodisability, including the transition from paediatric to adult healthcare. Although sibling participants were not actively involved in preparing transition plans, they were kept informed about steps that were being taken to help the sibling with a neurodisability prepare for transition. For example, they were aware about the resources that were being accessed by the family.

Future plans also included steps of what might happen when their parents passed away. Some families discussed that the sibling participants were not expected to become the official guardians, but they would have a prominent role in deciding who the official guardians might be. For other sibling participants, guardianship was not openly discussed but they thought about the possibility that they might become the official guardians.

4.3.3 | Making adjustments

Sibling participants were constantly reflecting and making adjustments to their short-term and long-term plans. When their sibling with a neurodisability first received a diagnosis, some sibling participants made adjustments in which they asked their parents if they could provide support. For example, picking up or being at home with their sibling with a neurodisability. Sometimes these adjustments in plans required negotiation between siblings and family members, such as whether someone else could take on responsibilities for the day. In many families, there was ongoing communication about adjustments to plans especially during the COVID-19 pandemic. When interviews were conducted with sibling participants, lockdown measures were in place where individuals were required to stay at home and limit their in-person activities. Due to these measures, schools shifted to provide virtual online classes (Ontario Newsroom, 2020). Many siblings with a neurodisability struggled with the lack of routine at home when schools were closed. Families had to communicate that the lockdown measures and school closures were temporary, and there would be an opportunity for the siblings to return to school in-person soon. Sibling participants struggled with how to communicate with their sibling with a neurodisability about plans. They realized that when lockdown restrictions were lifted, they would likely move away from home again and they needed to prepare their sibling with a neurodisability for this change. In many families, conversations were already taking place with the sibling with a neurodisability prior to the COVID-19 pandemic but the pandemic provided some more time for the siblings with a neurodisability to adjust to plans.

4.3.4 | Seeking support

All sibling participants discussed seeking support for their mental health and well-being. Sibling participants experienced a spectrum of emotions. It was common across participants to experience feelings of guilt when they had negative reactions (e.g., frustration, sadness and annoyance) towards their sibling with a neurodisability. An older

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

sister describes the guilt that she feels when she spends time with friends:

> Even though there's a sense of, in the moment when I'm refusing to go out "I wish I can go" and the presence of guilt almost that I can't go, but when I come out and see [name of sibling with cerebral palsy], yeah, this is what I'm doing it for. And then even when I am out with my friends… there's a sense of guilt… because I keep thinking in my head, "Like okay, I should be at home, I wonder if [name of sibling with cerebral palsy] is okay"
>
> (Older sister of a brother with cerebral palsy).

Sibling participants sought different resources to manage and cope with their emotions. During childhood, sibling participants often shared their emotions with their parents. They frequently turned to their mothers for emotional support who could provide comfort and information to explain the behaviour of the sibling with a neurodisability. As sibling participants grew up, they turned to their older siblings for advice and support. For sibling participants who did not have other siblings in the family, they often sought therapy from healthcare professionals. Some sibling participants felt that they could connect with friends who were also siblings of individuals with a neurodisability, because they had similar experiences and could share advice. Support was critical for all sibling participants to cope with the array of emotions that they felt as a sibling of an individual with a neurodisability.

5 | DISCUSSION

This study identified how sibling participants had different roles that evolved into emerging adulthood. Some of these roles have been described in an online survey completed by adult siblings of individuals with intellectual and developmental disabilities (Hall & Rossetti, 2018), and this study identified other roles such as a role model/mentor, protector, and supporter roles. This study further builds on existing literature in which intrapersonal characteristics, including their personal identity, values, and experiences, influenced the roles that sibling participants had to their sibling with a neurodisability. Other studies identified similar variables that influenced how typically developing siblings chose to have the specific role as a caregiver (Burke et al., 2012; Lee & Burke, 2018; Saxena, 2015). Adult siblings were expected to provide future care if they had no other siblings, identified as female, lived close in proximity and had a close emotional relationship with their sibling with an intellectual or developmental disability (Burke et al., 2012; Lee & Burke, 2018). Many sibling participants in this study who identified as female and were the only typically developing sibling in the family were already a caregiver or were expected to have this role in the future.

This study also identified that siblings had a distinct process in how they decided on their roles. Previous studies focused on the perspectives of adult siblings about their plans with caregiving to their sibling with a disability (Heller & Arnold, 2010; Lee et al., 2019; Lee & Burke, 2018). At the microsystem at the level of the family, siblings are in a unique position as the 'sandwich' in which they may consider how they could care for their sibling with a neurodisability, and also their ageing parents (Lee et al., 2020; Riley & Bowen, 2005). Often, there are few discussions in the family about future planning (Davys et al., 2015; Griffiths & Unger, 1994; Heller & Kramer, 2009). Some families, similar to the experiences of sibling participants, may choose not to have discussions about future plans because the event for changes in roles appears to be in the far-off future (Burke et al., 2012). The perspectives of sibling participants in this study further adds to the literature in that families might not have discussions about future planning, but sibling participants as young as age 14 were already having these thoughts. Despite the need for discussions about future planning with the whole family, a previous review of the grey literature about resources for siblings to support with healthcare management identified no resources to facilitate family conversations for future planning (Nguyen et al., 2021). Members of the SibYAC described the valuable role that they have to their sibling with a disability, and there should be conversations with parents, service providers and professionals about these roles (Bellefeuille et al., 2021). Healthcare professionals can ask questions about the roles that different family members have with the youth with a neurodisability, and to continue to have these ongoing conversations. Parents can also include siblings in the discussions to plan for the transition of the youth with a neurodisability to adulthood, including how to navigate services in healthcare, education and/or employment. When all family members are supported in their roles, a positive family environment can be promoted that contributes to the health and well-being of the youth with a neurodisability and overall family (Gorter et al., 2014).

At the macrosystem at the level of programs, support is required for the emotional health and well-being of siblings, as described by sibling participants and the SibYAC (Bellefeuille et al., 2021). All sibling participants received support from different sources, such as their peers with or without a sibling with a neurodisability, parents, or healthcare professionals. In Canada, siblings of individuals with a neurodisability can receive support in different ways, such as connecting with support groups; for example in Canada, there are Sibshops for ages 8–13 years old (D'Arcy et al., 2005) and Siblings Canada for adult siblings (Siblings Canada, 2024) with limited resources to support siblings ages 14 to 25 years old. There needs to be recognition in Canada that informal caregivers can include siblings of individuals with a neurodisability. For siblings who have the role of a caregiver to their sibling with a neurodisability, community supports could include informal groups to connect siblings with each other, financial assistance such as a tax credit for medical and disability-related expenses, and rights to request employment accommodations such as flexible work schedules or time off from work when needed (Torjman, 2015).

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

5.1 | Strengths and limitations

A strength of this study is the engagement of the SibYAC to inform all aspects of the study. Their involvement informed the need for this study as well as how to design the study to recruit and engage with sibling participants during the interviews. For example, the SibYAC supported the use of photo elicitation and graphic elicitation of relational maps and these techniques were beneficial to encourage sibling participants to share their experiences in-depth. A second strength was the involvement of our multidisciplinary team and SibYAC who provided insights to elucidate key themes that captured the multilayered factors that influenced how typically developing siblings chose different roles during the trajectory to emerging adulthood.

A limitation of this study was that most sibling participants were females who were older than their sibling with a neurodisability and may have more interest in sharing their roles compared to siblings who did not participate. Based on the literature, female siblings often plan to become future caregivers to their sibling with a neurodisability (Burke et al., 2012; Lee & Burke, 2018). While the older sisters in this study described a detailed level of care such as assistance with personal hygiene and therapy, the older brothers also described how they provide care such as being informed about medications or taking care of their sibling with a neurodisability after school. This study provides a deep understanding of how siblings processed their decision to become caregivers. Another limitation is that multiple family members such as the youth with a neurodisability and parents/caregivers could have been interviewed to understand their perspectives about the roles of siblings in the family. This study only focused on the perspectives of siblings about their roles. An additional limitation is that the different diagnoses of the sibling with a neurodisability can have a wide spectrum of potential outcomes and impacts on the sibling(s) and families.

5.2 | Future directions

This study described the perspectives of siblings and identified a need to develop resources to support siblings in their roles. A next step is to co-develop resources with multidisciplinary interested parties (e.g., siblings, parents and healthcare professionals) who could potentially help siblings in their roles who can then support their sibling with a neurodisability during the transition to adulthood. This developmental period during the transition to adulthood is a critical time period where the person and environment is changing, and a positive support system can optimize the growth of the person (Gorter et al., 2014). The SibYAC identified that there are limited support groups for young adult siblings ages 14 to 25 years old. They reflected on the personal value of being a part of this advisory council, which has become a support network for them.

A second step is to conduct further research to understand the impact of specific diagnoses on the whole family, including sibling(s). Further research should also be conducted about the intersection between personal, cultural, and family values that can influence the roles of siblings of youth with a neurodisability. This study provided preliminary information about how these values affect the initial step to the selection of sibling roles. For example, certain cultures emphasize familial responsibility in which siblings may feel an obligation to have a caregiver role to their sibling with a neurodisability (Saxena, 2015; Smith et al., 2007). Sibling participants also identified their personal values and so, a further understanding is needed about how different values are connected and formed to influence sibling roles.

6 | CONCLUSION

Since childhood, siblings are navigating roles and responsibilities to their sibling with a neurodisability. These roles continue to change during a time when both siblings and their sibling with a neurodisability were transitioning to adulthood. Each role comes with its own emotional responsibility, yet all siblings want to provide the best care to their sibling with a neurodisability. Future resources are needed to prepare and support siblings as they transition to their roles.

ACKNOWLEDGEMENTS

We are grateful to the siblings who participate in this study. We gratefully acknowledge our partnership with the Sibling Youth Advisory Council (SibYAC) throughout all study phases; all members were asked about their level of involvement and chose whether they wanted to have a co-authorship role. We also thank our colleagues who are part of our qualitative health research and mixed methods group as our expert consultants who took part in our peer debriefing process for data analysis. We are grateful to the Canadian Institutes of Health Research and the CHILD-BRIGHT Network for their funding support for this work.

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest.

DATA AVAILABILITY STATEMENT

All data to support the findings of this study are provided in the paper.

ETHICS STATEMENT

This study received ethical approval from the Hamilton Integrated Research Ethics Board (Project #7932).

INFORMED CONSENT

All study participants provided informed consent.

ORCID

Linda Nguyen https://orcid.org/0000-0002-7165-6678
Susan M. Jack https://orcid.org/0000-0003-4380-620X
Hanae Davis https://orcid.org/0000-0003-3274-8796
Briano Di Rezze https://orcid.org/0000-0002-6061-2506
Marjolijn Ketelaar https://orcid.org/0000-0002-8324-518X
Jan Willem Gorter https://orcid.org/0000-0002-3012-2119

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

REFERENCES

Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities*, *50*(5), 373–382. https://doi.org/10.1352/1934-9556-50.5.373

Atkin, K., & Tozer, R. (2014). Personalisation, family relationships and autism: Conceptualising the role of adult siblings. *Journal of Social Work*, *14*(3), 225–242. https://doi.org/10.1177/1468017313476453

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, *13*(2), 544–559.

Bellefeuille S, Davis H, Havens J., Nguyen L. CanChild Luke's legacy family research rounds: The art of sibling science [internet]. 2021 [cited 2022 Mar 2]. Available from: https://vimeo.com/543787118

Blum, R. W. (2002). Introduction. *Pediatrics*, *110*(Supplement 3), 1301–1303. https://doi.org/10.1542/peds.110.S3.1301

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Bronfenbrenner, U. (1992). In R. Vasta (Ed.), *Six theories of child development: Revised formulations and current issues* (pp. 187–249). Jessica Kingsley Publishers.

Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *117*(1), 33–47. https://doi.org/10.1352/1944-7558-117.1.33

Canadian Institutes of Health Research. (2019). Strategy for patient-oriented research - patient engagement framework - CIHR. [cited 2023 Mar 26]. Available from: http://www.cihr-irsc.gc.ca/e/48413.html

Canadian Institutes of Health Research. *Patient engagement [Internet]*. 2019 [cited 2022 Apr 19]. Available from: https://cihr-irsc.gc.ca/e/45851.html

CanChild Centre for Childhood Disability Research. *BrothErs and sisters involvement in health care TranSition for youth wIth brain-based disabilitieS (BEST SIBS) study [internet]*. 2021 [cited 2022 Feb 4]. Available from: https://canchild.ca/en/research-in-practice/current-studies/brothers-and-sisters-involvement-in-health-care-transition-for-youth-with-brain-based-disabilities-best-sibs-study

CHILD-BRIGHT Network. *About us: What is CHILD-BRIGHT? [internet]*. 2019 [cited 2022 Apr 18]. Available from: https://www.child-bright.ca/what-is-child-bright

CHILD-BRIGHT Network. *Guidelines for patient partner compensation [internet]*. 2020 [cited 2022 Apr 6]. Available from: https://www.child-bright.ca/compensation-guidelines

Copeland, A. J., & Agosto, D. E. (2012). Diagrams and relational maps: The use of graphic elicitation techniques with interviewing for data collection, analysis, and display. *International Journal of Qualitative Methods*, *11*(5), 513–533. https://doi.org/10.1177/160940691201100501

D'Arcy, F., Flynn, J., McCarthy, Y., O'Connor, C., & Tierney, E. (2005). Sibshops. An evaluation of an interagency model. *Journal of Intellectual Disabilities*, *9*(1), 43–57. https://doi.org/10.1177/1744629505049729

Davys, D., Mitchell, D., & Haigh, C. (2015). Futures planning - adult sibling perspectives. *British Journal of Learning Disabilities*, *43*(3), 219–226. https://doi.org/10.1111/bld.12099

Forsythe, L. P., Carman, K. L., Szydlowski, V., Fayish, L., Davidson, L., Hickam, D. H., Hall, C., Bhat, G., Neu, D., Stewart, L., Jalowsky, M., Aronson, N., & Anyanwu, C. U. (2019). Patient engagement in research: Early findings from the Patient-Centered Outcomes Research Institute. *Health Affairs*, *38*(3), 359–367. https://doi.org/10.1377/hlthaff.2018.05067

Freeman, M., Stewart, D., Cunningham, C. E., & Gorter, J. W. (2018). Information needs of young people with cerebral palsy and their families during the transition to adulthood: A scoping review. *Journal of Transition Medicine [Internet]*, *1*(1), 1–16. Available from: https://www.degruyter.com/view/j/jtm.ahead-of-print/jtm-2018-0003/jtm-2018-0003.xml. https://doi.org/10.1515/jtm-2018-0003

Gorter, J. W., Amaria, K., Kovacs, A., Rozenblum, R., Thabane, L., Galuppi, B., Nguyen, L., Strohm, S., Mahlberg, N., Via-Dufresne Ley, A., & Marelli, A. (2021). CHILD-BRIGHT READYorNot brain-based disabilities trial: Protocol of a randomised controlled trial (RCT) investigating the effectiveness of a patient-facing e-health intervention designed to enhance healthcare transition readiness in youth. *BMJ Open*, *11*, 48756. https://doi.org/10.1136/bmjopen-2021-048756

Gorter, J. W., Stewart, D., Smith, M. W., King, G., Wright, M., Nguyen, T., Freeman, M., & Swinton, M. (2014). Pathways toward positive psychosocial outcomes and mental health for youth with disabilities: A knowledge synthesis of developmental trajectories. *Canadian Journal of Community Mental Health*, *33*(1), 45–61. https://doi.org/10.7870/cjcmh-2014-005

Griffiths, D. L., & Unger, D. G. (1994). *Views about planning for the future among parents and siblings of adults with mental retardation* (Vol. 43, pp. 221–227). National Council on Family Relations.

Hall, S. A., & Rossetti, Z. (2018). The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, *31*(3), 423–434. https://doi.org/10.1111/jar.12421

Hayden, N. K., Hastings, R. P., & Bailey, T. (2023). Behavioural adjustment of children with intellectual disability and their sibling is associated with their sibling relationship quality. *Journal of Intellectual Disability Research*, *67*(4), 310–322. https://doi.org/10.1111/jir.13006

Heller, T., & Arnold, C. K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(1), 16–25. https://doi.org/10.1111/j.1741-1130.2010.00243.x

Heller, T., & Kramer, J. (2009). Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual and Developmental Disabilities*, *47*(3), 208–219. https://doi.org/10.1352/1934-9556-47.3.208

Kids Brain Health Network. *Overview [internet]*. 2021 [cited 2022 Apr 18]. Available from: https://kidsbrainhealth.ca/index.php/about/overview/

Lee, C., Burke, M. M., Arnold, C. K., & Owen, A. (2020). Compound sibling caregivers of individuals with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 1069–1079. https://doi.org/10.1111/jar.12729

Lee, C., Burke, M. M., & Stelter, C. R. (2019). Exploring the perspectives of parents and siblings toward future planning for individuals with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *57*(3), 198–211. https://doi.org/10.1352/1934-9556-57.3.198

Lee, C. E., & Burke, M. M. (2018). Caregiving roles of siblings of adults with intellectual and developmental disabilities: A systematic review. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(3), 237–246. https://doi.org/10.1111/jppi.12246

Manafo, E., Petermann, L., Mason-Lai, P., & Vandall-Walker, V. (2018). Patient engagement in Canada: A scoping review of the 'how' and 'what' of patient engagement in health research. *Health Research Policy and Systems*, *16*(1), 5. https://doi.org/10.1186/s12961-018-0282-4

McCormick, M., & Schleifer, M. (2020). Responsibility for beliefs and emotions. *Paideusis*, *15*(1), 75–85. https://doi.org/10.7202/1072695ar

Meleis, A. I., Sawyer, L. M., Im, E. O., Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, *23*(1), 12–28. https://doi.org/10.1097/00012272-200009000-00006

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

Morris, C., Janssens, A., Tomlinson, R., Williams, J., & Logan, S. (2013). Towards a definition of neurodisability: A Delphi survey. *Developmental Medicine and Child Neurology*, *55*(12), 1103–1108. https://doi.org/10.1111/dmcn.12218

Nguyen, L., Davis, H., Bellefeuille, S., Havens, J., Jack, S. M., Di Rezze, B., Ketelaar, M., & Gorter, J. W. (2021). Canadian resources for siblings of youth with chronic health conditions to inform and support with healthcare management: A qualitative document analysis. *Frontiers in Rehabilitation Sciences*, *2*, 52. https://doi.org/10.3389/fresc.2021.724589

Nguyen, L., Jack, S. M., Di Rezze, B., Ketelaar, M., & Gorter, J. W. (2021). Protocol of the BEST SIBS study: A qualitative case study to investigate the roles and responsibilities of siblings of youth with a neurodisability during health care transition. *Journal of Transition Medicine*, *3*(1), 1–11. https://doi.org/10.1515/jtm-2021-0004

Novak-Pavlic, M., Gorter, J. W., Phoenix, M., Micsinszki, S., Pozniak, K., Li, L., Nguyen, L., Soper, A. K., Kwok, E. Y. L., Bootsma, J. N., Buchanan, F., Davis, H., Malek, S. A., van Meeteren, K. M., & Rosenbaum, P. L. (2023). Patients and families as Partners in Patient-Oriented Research: How should they be compensated? *Journal of Patient-Centered Research and Reviews*, *10*(2), 82–90. https://doi.org/10.17294/2330-0698.1975

Ontario Brain Institute. (2019). *Ways community members can participate in the stages of research*. 2019 [cited 2023 Feb 21]. Available from: https://braininstitute.ca/img/Patient-engagement-in-the-stages-of-research.pdf

Ontario Newsroom. (2020). *Ontario announces provincewide shutdown to stop spread of COVID-19 and save lives*. 2020 [cited 2023 Aug 2]. Available from: https://news.ontario.ca/en/release/59790/ontario-announces-provincewide-shutdown-to-stop-spread-of-covid-19-and-save-lives

Patton, M. Q. (1990). Designing qualitative studies. In *Qualitative evaluation and research methods* (pp. 145–198). Sage Publications Inc.

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research*, *34*(5 Pt 2), 1189–1208.

Redquest, B. K., Tint, A., Ries, H., Goll, E., Rossi, B., & Lunsky, Y. (2020). Support needs of Canadian adult siblings of brothers and sisters with intellectual/developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(3), 239–246. https://doi.org/10.1111/jppi.12339

Riley, L. D., & Bowen, C. (2005). The sandwich generation: Challenges and coping strategies of multigenerational families. *The Family Journal*, *13*(1), 52–58. https://doi.org/10.1177/1066480704270099

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, *11*(1), 25–41. https://doi.org/10.1080/14780887.2013.801543

Sankowski, E. (1977). Responsibility of persons for their emotions. *Canadian Journal of Philosophy*, *7*(4), 829–840. https://doi.org/10.1080/00455091.1977.10716199

Sawyer, S. M., Azzopardi, P. S., Wickremarathne, D., & Patton, G. C. (2018). The age of adolescence. *The Lancet Child & Adolescent Health*, *2*(3), 223–228. https://doi.org/10.1016/S2352-4642(18)30022-1

Saxena, M. (2015). Variables that can enhance and complicate sibling caregiving of individuals with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *12*(3), 210–219. https://doi.org/10.1111/jppi.12127

Siblings Canada. (2024). *Siblings Canada – Canadian Centre for Caregiving Excellence [internet]*. [cited 2022 Sep 19]. Available from: https://canadiancaregiving.org/siblingscanada/

Smith, M. J., Greenberg, J. S., & Seltzer, M. M. (2007). Siblings of adults with schizophrenia: Expectations about future caregiving roles. *American Journal of Orthopsychiatry*, *77*(1), 29–37. https://doi.org/10.1037/0002-9432.77.1.29

Smits, D. W., van Meeteren, K., Klem, M., Alsem, M., & Ketelaar, M. (2020). Designing a tool to support patient and public involvement in research projects: The involvement matrix. *Research Involvement and Engagement*, *6*(1), 30. https://doi.org/10.1186/s40900-020-00188-4

Stewart, D. (2009). Transition to adult services for young people with disabilities: Current evidence to guide future research. *Developmental Medicine and Child Neurology*, *51*(Supp. 4), 169–173. https://doi.org/10.1111/j.1469-8749.2009.03419.x

Torjman, S. (2015). *Policies in support of caregivers*. Available from: https://maytree.com/wp-content/uploads/1071ENG.pdf

Tucker, C. J., McHale, S. M., & Crouter, A. C. (2001). Conditions of sibling support in adolescence. *Journal of Family Psychology*, *15*(2), 254–271. https://doi.org/10.1037/0893-3200.15.2.254

Wang, C. C., & Redwood-Jones, Y. A. (2001). Photovoice ethics: Perspectives from Flint Photovoice. *Health Education & Behavior : the Official Publication of the Society for Public Health Education*, *28*(5), 560–572. https://doi.org/10.1177/109019810102800504

Yin, R. K. (2018). Designing case studies: Identifying your case(s) and establishing the logic of your case study. In *Case study research and applications: Design and methods. Thousand oaks* (pp. 25–78). Sage Publications Inc.

Zarrett, N., & Eccles, J. (2006). The passage to adulthood: Challenges of late adolescence. *New Directions for Youth Development*, *2006*(111), 13–28. https://doi.org/10.1002/yd.179

How to cite this article: Nguyen, L., Jack, S. M., Davis, H., Bellefeuille, S., Arafeh, D., Di Rezze, B., Ketelaar, M., & Gorter, J. W. (2024). Being a sibling of a youth with a neurodisability: A qualitative study about the roles and responsibilities during the transition to adulthood. *Child: Care, Health and Development*, *50*(2), e13241. https://doi.org/10.1111/cch.13241

13652214, 2024, 2, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/cch.13241 by Utrecht University, Wiley Online Library on [22/05/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License