



The Experiences of Young Sibling Carers: A Qualitative Study

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Abstract

Few studies have explored young sibling caregiving from the perspective of young carers. The aim of this study was to explore the unique experiences and challenges of young people in Ontario, Canada who care for a sibling. Data were obtained from interview-style podcasts titled *Hidden: The Voices of Young Carers* published by “The Change Foundation”. A total of seven podcasts were transcribed, coded, and analyzed using thematic analysis. Eight themes were identified. While young sibling carers described an enhanced level of resourcefulness resulting from their role when compared to their peers, they also noted the unique challenges that emanate from being a young sibling caregiver. Limitations and implications of the analysis are discussed. Future directions for research are also explored.

Keywords: caregiving, sibling caregiving, young carer, thematic analysis, qualitative

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Introduction

One in four young Canadians (1.18 million) aged 15 to 29 provide care to a family member or friend with a health condition, aging needs, or disability (Statistics Canada, 2012). Young carers are “children and adolescents who have to take a primary caregiving role within the family regardless of their age or capabilities” (Charles, 2011, p. 27). Care is most often provided to grandparents, parents, and siblings, but also to non-relatives, such as friends. Approximately 50% of young carers spend 2-9 hours per week caring for family and friends and 20% spend more than 10 hours. Caregiving by young people has increased in the last two decades and is expected to grow due to the aging population, higher rates of women’s employment, and shifting family structures (i.e., more extended family members cohabiting) (Statistics Canada, 2012).

Being a young carer can be a rewarding and meaningful experience. Young caregivers report feeling higher levels of maturity, a sense of purposefulness, worthiness, selflessness, and importance, self-efficacy, compassion, confidence and competence (Berardini et al., 2021; Remtulla et al., 2012; Szafran et al., 2016). At the same time, caregiving responsibilities may adversely impact education, paid work, and physical and mental health of young carers (e.g., Namkung et al., 2017; Remtulla et al., 2012; Statistics Canada, 2012). One study found that compared to their non-caregiving peers who typically spend 2 hours per week helping around the home, young carers spend approximately 7-27 hours per week participating in caregiving duties (Lakman et al., 2017). Young carers are also unique as compared to adult carers, and as such, the term *young carer penalty* has been established to encompass the challenges and disadvantages that this population experiences when it comes to employment and educational pursuits, familial, social, and emotional livelihood (Stamatopoulos, 2018). Young carers are at a critical stage of emotional, physical, and mental development and are in the process of clarifying and solidifying their priorities and plans for the future. Taking on a caregiving role may interfere with educational and career pursuits and delay leaving a family home, getting married, having children, and other developmental tasks (Levine et al., 2005). One in five young carers report that their schoolwork has suffered because of their caregiving duties, and research reveals the positive correlation between time spent caregiving and limited future aspirations (Lakman et al., 2017; Statistics Canada, 2012). More than one third of young carers report being absent from work due to caregiving obligations (Statistics Canada, 2012). Caregiving may also take a toll on a caregiver’s emotional, mental, and physical health (Statistics Canada, 2012). Young carers reported feelings of guilt, isolation, depression, substance abuse, self-injury, and being burdened and overwhelmed by caring responsibilities, among other concerns (Charles, 2011; Remtulla et al., 2012). Additionally, while engaging in self-compassion and self-care are recognized as important in their lives, these practices are often neglected due to time constraints, as well as feelings of guilt and selfishness for taking time for themselves (Berardini et al., 2021).

Despite these numerous adverse impacts and high prevalence rates, caregiving by young people has been neglected by scholars, policy makers, health care professionals, and other stakeholders. Hendricks et al. (2021) reported that in the United States only four new peer-reviewed articles on young carers were published over the course of six years, highlighting the need for increased awareness and provision of supports for this population. As such, young carers are often referred to ‘hidden’ (Smyth et al., 2011) or ‘invisible’ (Robson, 2000). Canada has been

slower than other countries in recognizing and addressing the needs of young carers, as evidenced by nearly non-existent legislative supports and funding (Stamatopoulos, 2016). In academia, young carers are largely excluded from a substantial body of research on adult caregiving (Stamatopoulos, 2018). One reason for this lack of attention is prevailing social and cultural ideals about young carers and the expectations of what encompasses a “caregiver” (Kavanaugh & Stamatopoulos, 2021). Young carers may not recognise themselves as carers or be recognized by others (Smyth et al., 2011). This is because culturally, young people are often not expected to be carers but rather care recipients given the social constructs of their position in families and society (Kavanaugh & Stamatopoulos, 2021). Also, young carers may provide care for a family member out love, and caregiving may be seen as an aspect of a loving relationship and not as labor. Overall, young carers remain hidden and out of reach of services and supports as countries around the globe have failed to develop legal rights and policy interventions that are tailored to young carers’ needs and that support their positive psychosocial and physical health and development (Kavanaugh & Stamatopoulos, 2021; Leu & Becker, 2017; Robson, 2000; Smyth et al., 2011). The current study seeks to address this gap by qualitatively investigating the experiences of Canadian young carers. Our focus is on young people caring for their sibling(s). Siblings, particularly those facing a long-term health condition or disability, are common recipients of young carers’ support and care (Statistics Canada, 2012).

The sibling relationship can be one of the strongest bonds to occur over the life course (Park & Lee, 2017), and multiple dimensions contribute to the uniqueness of this bond. Specifically, siblings have shared life experiences, common genetic backgrounds, intimacy, mirrored experience, validation and belonging, as well as competition (Cicirelli, 1995). In addition, the sibling relationship impacts the formation of siblings’ identity, self-esteem, and adjustment (Cicirelli, 1995; Yeh & Lempers, 2004). Siblings often turn to one another in times of need by providing care to each other. Siblings may offer care as an extension of values learned from within the family and in situations where there is illness, disability, or unavailable parents (Willyard et al., 2008). Young sibling caregivers take on this role to assist their parents when they have their own illnesses, struggle with substance abuse, or are absent from family life due to work or other social commitments (Stamatopoulos, 2015). Sibling carers may provide emotional, instrumental, informational, and other types of support (Yeh & Lempers, 2004).

The impacts of young sibling caregiving parallel findings from general young caregiving and sibling caregiving literature. Young sibling carers tend to experience distress and burden to their psychological and social well-being, struggles with feelings of accomplishment, independence, and maturity (Barry, 2011; Stamatopoulos, 2016; Szafran et al., 2016). Young carers may experience inner tension between having to care for a sibling and not wishing to be a carer to a sibling (Reinhard & Horwitz, 1995). Sibling caregivers may also experience feelings of embarrassment, guilt, and feel neglected and unsupported by parents and health care providers. Healthcare professionals may fail to involve siblings in a patient’s (child’s) care due to the expectation that siblings will not take on an active caregiving role for their brother or sister (Namkung et al., 2017; Reinhard & Horwitz, 1995). When comparing the well-being of caregiving and non-caregiving siblings, research reveals that sibling caregivers experience more depression, poorer health, lower levels of life satisfaction, and decreased perceived control over their lives (Namkung et al., 2017). In one study it was shown that, as adults, sibling caregivers were less likely to be married and employed than non-caregivers (Namkung et al., 2017).

The existing literature on sibling caregiving focuses mainly on siblings in adulthood, and less frequently on younger sibling caregivers. The scarce research that is available regarding young sibling caregiving experiences centres on retrospective accounts by adults of their past caregiving experiences (e.g., Lackey & Gates, 2001; Szafran et al., 2016). Arguably, young people may more clearly and vividly articulate their current circumstances, experiences, and needs than years later as adults. Ideally, services are tailored to the experiences and needs as expressed by service users. Furthermore, existing work on young carers does not consider who the care recipients are (friends, siblings, etc.), potentially overlooking differences that may arise from caring for a specific care recipient. As a result, young sibling carers' experiences may be generalized into the larger population of young carers. There is evidence that young sibling carers may have aspects of their experiences that differ from young carers more broadly. For example, Park & Lee (2017) identified some unique features in caring for a sibling (e.g., a young carer's worries that they may develop the same illness as their sibling or that they may not be able to ever develop a life separate from caring for a sibling). Since young carers appear to experience a unique set of challenges and opportunities that stem from their developmental stage and the nature (i.e., social and biological) of the sibling bond, more detailed work is needed that specifies *how* sibling carers make sense of their experiences. Doing so may help identify the unique differences that this population faces, may increase their visibility thereby generating greater research and awareness on this group, and produce better interventions and supports for them. This may alleviate the burden associated with caring for a sibling, heighten positive aspects, and provide society with a deeper understanding of what it means to be a young sibling caregiver.

To address this gap, the current study qualitatively explored how young Canadians under the age of 25 make sense of caring for their sibling(s). Thematic analysis (Braun & Clarke, 2006, 2021) was used to identify key themes of the sibling caregiver experience. We analyzed existing podcasts involving interviews with young carers who currently provide care to their sibling(s). These podcasts or digital audio files available on the internet, were recorded as a series focused on young caregiving. Multiple young sibling carers were interviewed about their caregiving experiences.

Methods

Data Collection

The data for the present study came from The Change Foundation's podcast series titled *Hidden: The Voices of Young Carers*. Podcasts are digital audio files that are accessed "on-demand" through the Internet for downloading or streaming onto a computer or mobile device. While podcasts are most used as a mode of communication, they may also be implemented in research throughout data collection and analysis processes, in critical inquiry, and for the mobilization of knowledge (Day et al., 2017). The process of analyzing podcasts invokes a deeper engagement with the data as listening and playing back podcasts numerous times allows for a greater degree of reflexivity that may be dismissed when reviewing written text (Kinkaid et al.,

2020). In each episode of *Hidden: The Voices of Young Carers* a different young carer is invited to communicate their experiences to the host, who prompts guests with questions surrounding their unique depictions of caregiving.

Podcasts were accessed through public streaming platforms (e.g., Apple Podcasts). The podcast episodes that were selected included young carers who were 25 years old or younger at the time of recording. Additionally, only those who provided care for a sibling(s) were included in the study. All young carers who participated in the podcasts were residents of Ontario, Canada. Of the 13 episodes in the series, a total of seven podcasts met the inclusion criteria and were selected for the study. The podcasts ranged from nine to eighteen minutes in length. Although the podcasts themselves did not conceal the anonymity of interviewees, we removed all identifying information. Interviewees' ages ranged from 8-25 years old. Young carers in this study provided care for their siblings who faced various health challenges including, chronic pain, developmental disabilities, autism spectrum disorder, and neurological and mental health disorders. Demographic data were not disclosed by the participants or presented by the publisher.

Data Analysis

Thematic analysis (Braun & Clarke, 2006, 2021) was used to analyze the podcast interview transcripts. Thematic analysis is a qualitative research method used to identify themes or patterns in the data (Clarke & Braun, 2017). We used Braun and Clarke's (2006) six phases to analyze the data. The first author familiarized herself with the data by transcribing podcasts and re-reading the transcripts. She also made notes on her initial impressions of the data. In the second phase she began manually generating the initial codes which involved organizing the data into meaningful groups. Following this, she began sorting codes into potential themes by assembling all relevant coded data to each identified candidate theme and considering how the codes may be joined to form overarching themes. Next, she reviewed the themes to ensure that they were related to the initial codes and the entire data set. In this phase, a thematic "map" of the analysis was created to help with the refinement of themes. Defining and naming themes followed, where she made her final refinement of details for each theme and generated names for each theme. Finally, she created the final report which involved using examples from the data and relating the analysis back to the research question. She consulted the second author during later stages of analysis.

Rigor

The following rigour criteria were used in the study: credibility, dependability, transferability, and confirmability (Lincoln & Guba, 1985). *Credibility* concerns whether conclusions seem plausible (Lincoln & Guba, 1985). To achieve credibility, the first author used prolonged engagement with the data; she listened to podcasts and read the original transcript multiple times. *Dependability* concerns the study's integrity or authenticity or whether the analysis process is in line with the accepted standards and can be trusted. Dependability in this study was fostered through keeping the audit trail or a detailed record of research activities (Morse, 2015).

Transferability concerns the extent to which the conclusions can be applied or transferred to another context or setting. Prolonged engagement, persistent observation, and ‘thick description’ were used to promote transferability (Morse, 2015). *Confirmability* concerns the fit between the participants’ displayed understandings and the researcher’s interpretations or conclusions (Lincoln & Guba, 1985). The first author displayed verbatim quotes alongside her analytic claims.

Results

We identified eight themes, including: *Enhanced Resourcefulness*, *Enhanced Responsibility*, *Emotionally and Practically Caring for the Sibling*, *Prioritising the Sibling’s Needs*, *Advocating for the Sibling*, *Balancing Roles*, *Social Judgment*, and *Challenges*.

Enhanced Resourcefulness

Interviewees shared gaining a greater sense of resourcefulness through their sibling caregiving experiences. Resourcefulness manifested in several ways, including through an increased sense of flexibility, patience, optimism, and perseverance. Interviewees reflected on how they learned to accept that their sibling’s challenges often pose limitations to their social and emotional interactions with each other. One way to help mitigate the effects of these challenges is through being flexible with siblings when participating in activities together. One of the interviewees (age 8), for example, stated, “you have to be more flexible and give them breaks and mini breaks, and if they don’t wanna share something with you then you have to be able to be okay with that and let them have it”. Enhanced flexibility and patience were also noted with respect to the time it takes for siblings to complete tasks. Interviewees reflected on their experiences of the level of patience they developed when engaging with their sibling, comparing their siblings’ needs to the needs of others who may not face the same challenges. The same interviewee as above described this like this: “sometimes I have to give her breaks when she acts up a bit over something that other people might not, and sometimes I have to be more like flexible with her... like give her extra time”. These quotations reflect a deepened sense of resourcefulness which was attributed by the interviewees to their sibling caregiving experiences.

Interviewees also commented on the importance of remaining optimistic while caring for siblings. One interviewee (age 15) stated:

I think definitely just trying to stay positive. It can be really hard but if you just try like you keep trying it’s just like something you really have to work on and as you get older, I think it becomes easier and just like seeing the brighter side of things even when it’s really hard.

This interviewee describes their experience of the hard work it takes to remain positive when

challenges arise in their caregiving experiences. Additionally, the ability to persevere through the challenges that interviewees experienced as young sibling carers was reflected in the interviews. One interviewee (age 25) described this like this:

You kind of have to like push through it and see the silver lining. I'm constantly reminding myself that this is making me stronger and my family is benefitting from this and they need my help and I'm helping them sustain a better quality of life by inputting my help so I try and remind myself of that whenever I'm feeling like garbage.

This interviewee discusses actively adopting a stance of persistence and perseverance as a carer—"pushing through" when it gets hard. Reflecting on how being in the role of a young carer benefits others seemed to mitigate the hardship experienced by this interviewee.

Enhanced Responsibility

Interviewees described an increased sense of responsibility through their caregiving experiences. In their accounts, young sibling carers compared themselves to their peers and noted discrepancies in levels of responsibility. One interviewee (age 16) saw responsibility as an aspect of identity and seemed to value this, stating:

...I think it's better in a sense like you gain responsibility and you learn how to take care of people a lot better than you know most people do. A lot of kids in my school use the term princesses or whatever that just kind of don't do anything but for me you kinda just gotta keep always keep moving.

This interviewee reflects on how having this higher level of responsibility is viewed as a positive impact that has come out of the caregiving role and something that is personally appreciated. The interviewee views their identity as different compared to the identity of classmates and experiences the idea of continuously moving forward despite the challenging nature of young sibling caregiving. Being responsible for or having to care for a sibling was described not as an extraordinary experience but a routine, 'normal' part of life. One interviewee (age 16) described this sense of normalcy as follows: "I've grown up in it so it's kind of like just normal to me that I think from the way I look at it is like my life is normal". This quote illustrates how being introduced to a caring role early in life creates a sense of caring as being an expected or normal aspect of life.

Emotionally and Practically Caring for the Sibling

Interviewees seemed highly attuned to, or aware of, their sibling's distress. They 'took on'

their sibling's distress and tried minimizing or preventing it. They shared thinking about and worrying for the sibling. One interviewee (age 15) expressed their concern or worry about their sibling like this:

...when I was in the same school as him, I stressed too much I was always worried like 'is he doing his work, is he behaving' and sometimes I wasn't able to go check on him cause the teachers wouldn't let me. So now that we're in different schools I can text him if I really need to.

This young sibling carer seems to feel responsible for ensuring the sibling's well-being and experiences distress when they are not able to communicate with, and care for, their sibling.

Sometimes caring for the sibling meant listening to and comforting them. Two siblings (carers, age 10) discussed providing emotional care to their sibling: "we help him when he's upset like after his sisters made a fight and went upstairs, he's upset, so we comfort him like we tell him that she didn't mean it and um that she should apologize and those type of stuff." Some interviewees discussed self-monitoring and modifying their own talk and actions to protect their siblings from distress. One interviewee (age 15) described this as follows:

I think definitely with some things I don't specify how much fun it was or exactly what I did cause I know she'd never be able to experience something like that and it's not like she'll be rude about it, it's just that I don't want to make her feel that way. But also, sometimes she likes it when I come home and tell her what I did because that's also fun for her hearing what I did.

This quote highlights how the young sibling caregiver works to limit their level of self-disclosure to minimize the pain of their sibling.

Interviewees also described providing practical or instrumental support to their siblings. Two siblings (age 10) expressed it as follows: "we help him a lot we help him into his wheelchair we help him with he's always trying to wear his glasses". Supporting one's sibling's functioning and skill development was another way to care for them. Supporting skill development entailed ensuring that the sibling is completing tasks, keeping up to date with homework, and functioning optimally. One interviewee (age 16) described this as:

I don't know it's been different than I guess some of my friends' household routines. You come home, you have to make sure they're doing something productive or trying to make sure that they're keeping up to date with everything.

This quote reflects that the young carer monitors their sibling's daily activities and ensures that their sibling stays on track.

Prioritising the Sibling's Needs

Interviewees discussed prioritizing caring needs of their siblings over their own needs and preferences. One interviewee (age 15) conveyed this as follows: “I’d rather stay home and spend time with her cause she’s not able to do those things and create those bonds and friendships with those people so sometimes we’re kind of the only people who she has”. This young sibling carer is aware of their siblings’ loss of social activities and relationships and highlights their commitment to their sibling’s social needs. Interviewees compared themselves to their siblings and shared feeling guilty for being the ‘well-sibling’ and having more opportunities in life. One interviewee (age 15) stated being aware of the discrepancies in available opportunities between them and their sister: “I definitely feel guilty if I’m going to that football game, cause she never really got to have those experiences and I just feel sometimes like why am I able to and she’s not”.

Advocating for the Sibling

Young sibling carers advocated for their siblings in public settings by standing up for them and confronting others’ negative attitudes and discriminatory behaviours. One interviewee (age 16) expressed this as:

We’ve been out and people have kind of looked at her in like different ways or something even when she’s not acting up and we kind of just call them out on it.... and some people will stare and you just gotta tell them off for it.

This quotation reflects how this interviewee has experienced public attention when out with their sibling and the need to challenge others’ negative attitudes. The interviewee seems to feel a sense of responsibility to protect and stand up for their sibling by confronting others who may be prejudiced or judgmental towards the sibling.

Balancing Roles

Interviewees discussed having to balance their caregiving role with their other (e.g., academic, social, and family) roles and negotiate priorities. Young sibling carers noted the challenges that they faced daily trying to negotiate competing roles and responsibilities. One interviewee (age 16) conveyed it like this:

I think it’s because since I’m managing school and then I’m managing my personal life which is a lot because of my brother. It gets difficult especially like with school, cause assignments start to pile up when I’m like focusing on my brother so it yeah it gets really tough at times when stuff gets really stressful even like if they had nothing to do with my brother, I would get really stressed but then I also know I have a responsibility to take care of my brother, so it gets hard.

This quote illustrates how caring for the sibling may be experienced as having adverse impacts on the carer's other areas of functioning, namely academic work. It reflects how their own personal pursuits become neglected, and how this is a distressing experience for them. Attempts to balance these various roles as a young sibling caregiver can often lead to feelings of inner tension. One interviewee (age 25) depicted it like this: "I try and remember that if I don't take care of myself then I won't be able to help out, I won't be any use to anybody so". This interviewee considers the importance of caring for the self to be able to care for others. There is an undertone of tension between one's own needs and the needs of others and an effort to rationalise or justify prioritizing oneself before others.

Social Judgement

Interviewees experienced social judgment in their roles as sibling caregivers. They discussed how social judgment manifested through a misunderstanding of their roles by society (e.g., friends, strangers, teachers, etc.) and as a result, engaged in the self-protective strategy of censoring in order to deal with these misinterpretations. Young sibling carers described feeling misunderstood in their caregiving role and others failing to acknowledge the positive aspects of caring for a sibling. One interviewee (age 15) characterized it like this:

Most people think that we do absolutely nothing and that is just- or like we're always sad and we like just sit there and are just down about what's going on, when in reality we've really just embraced what's going on in our lives and used it to our advantage and we've had so many amazing experiences.

This young sibling carer seems to feel misrepresented by others in the role. The interviewee also implies that others tend to focus on the more negative and stressful aspects of caregiving and overlook the positive features of what it means to be a young sibling carer. Other interviewees described that although their peers recognized them as sibling carers, they were unable to comprehend the extent of duties and responsibilities that were experienced by the interviewees. Another interviewee (age 25) illustrated this by saying: "... that's cool, they didn't understand the extent of it. They knew that I had a brother with special needs and that I had to stay with him sometimes. But they didn't realize what was going into it". For this interviewee, others do not fully understand (underestimate or take for granted) what it means to be a carer to a sibling.

To deal with misrepresentations of the young sibling caregiving experience, interviewees recalled censoring the information they would disclose to their peers which acted as a protective strategy to avoid negative implications of social judgment. One interviewee (age 15) described this as follows:

It's usually something I don't tell people. Like my best friend she's been my best friend since like grade 5, so she's grown to know these things but I'd never really like go out and tell someone just with the stigma and everything that people think that goes on.

This quotation depicts that anticipated social judgment or stigma from others prevents the young sibling carer from disclosing information about being a carer.

Moreover, interviewees also engaged in censoring information from authority figures (e.g., teachers) in moments when managing school became difficult. One interviewee (age 16) portrayed this as follows:

If she's sick or something late nights until like 2 in the morning you have school the next day, you go to school, what I find challenging you go to school and you're sitting in class and your eyes are getting heavy and you start passing out you didn't do your homework or something and they're like oh why didn't you do it and they start getting all mad with you and you kind of just have to like... I don't usually explain it cause I'll just say okay I didn't do my homework ... you have to go to school the next day and just have to act like everything's normal.

This interviewee indicates how they must hide the challenges of their caregiving reality from others in fear of judgment or misunderstanding.

Challenges

Interviewees discussed the challenges and pressures that they experience in their role as young sibling caregivers. This manifested through feelings of distress, embarrassment, and a perceived lack of control. Inner distress was evidenced through the loss of not adhering to the Western cultural ideas of family. One interviewee (age 16) described this as follows: "even today when I'm walking out on the street and we're just hanging out as a family, I see other kids and I'm like why can't my brother be like them". This interviewee illustrates how they experience inner tension when comparing themselves and their family system to what is depicted as 'normal'. There seems to be an underlying pressure to conform to these ideals and a sense of resentment that results from this divergence. The stressful nature of tolerating a sibling when distressed due to their ailments was also noted throughout podcast interviews. One interviewee (age 15) mentioned this as follows: "I have an older sister who has a bunch of different illnesses and problems but something she struggles the most with is chronic pain so sometimes her emotions could be let out on me which can be really stressful". It is clear from this quotation that being a young sibling carer is a challenging experience. This quote further highlights how this interviewee accepts this type of treatment and does not pursue a typical sibling argument when feeling mistreated.

An additional challenge reported across interviews was the inner tensions felt by young sibling caregivers for experiencing a sense of embarrassment towards their siblings' public outbursts. One interviewee (age 25) who cared for a sibling with developmental disabilities illustrated this as follows:

When he's really like hyped up, he doesn't like loud noises so when he gets around a big group of people um or people he doesn't really know well he kind of gets tense he'll like start yelling, it used to be really embarrassing like back in the day when we used to go to church and he'd like start yelling in the middle of church I'm like man.

Young sibling caregivers may find themselves receiving unwanted attention due to their sibling's behaviours or expressions of emotions in public settings, which leads to feelings of embarrassment and shame.

Finally, the experience of having little to no control was experienced as a challenge for young sibling carers. Specifically, interviewees found distressing not knowing how siblings may respond (emotionally and behaviourally) and being unable to control these reactions. One interviewee (age 16) who cared for a sibling with neurological and mental health disorders expressed this as follows: "Well some of them that I can recall are when he gets really angry with me, which are where he pulls my hair and that most part like we can't control his behaviour we don't know how he's going to react." This interviewee highlights their (and their family's) sense of helplessness when faced with the sibling's intense reactions. The feelings of being unable to control these reactions indicates the distressing and challenging nature of this role.

Discussion

We used thematic analysis to analyze seven interview-style podcasts to explore how young Canadians under the age of 25 living in Ontario, Canada make sense of their sibling caregiving experiences. Several themes were identified, including *Enhanced Resourcefulness*, *Enhanced Responsibility*, *Emotionally and Practically Caring for the Sibling*, *Prioritising the Sibling's Needs*, *Advocating for the Sibling*, *Balancing Roles*, *Social Judgment*, and *Challenges*. The study adds to the scarce literature on young Canadian sibling caregiving experiences. This is the first study that has explored online interview data specific to young sibling carers' accounts of their present caregiving experiences.

The theme of enhanced resourcefulness aligns with the positive impacts described in young sibling caregiving research (Charles, 2011; Remtulla et al., 2012; Stamatopoulos, 2018; Szafran et al., 2016). Interviewees elaborated on this theme by sharing instances that led to an increased degree of flexibility, patience, optimism, and perseverance. It seemed that underlying these factors was a sense of difficulty in maintaining these aspects of resourcefulness (i.e., especially when feeling exhausted) mixed with pride and appreciation for having developed these skills.

Aligning with the prior work (Charles, 2011; Stamatopoulos, 2016; Stamatopoulos, 2018; Szafran et al., 2016), interviewees in the present study shared their experiences of enhanced responsibility resulting from their caregiving role. It was through making comparisons of their own duties when considering their peers, that young sibling carers recognized the value in these experiences. This parallels young sibling carer research that illustrates the positive implications of being in this role. For example, in their qualitative analysis of retrospective accounts of young

sibling caregiving, Szafran et al. (2016) found that benefits of being responsible at a young age included acquiring a sense of independence, community responsibility, the ability to problem solve, and an enhanced ability to make career choices. In the current study, the interviewees' willingness to participate in podcasts on young carers may reflect their community responsibility and motivation to be leaders of change by generating greater attention and awareness of young carers in Canada. Seeing value in their increased responsibilities may also speak to the increased sense of maturity, personal growth, and identity formation that young carers generally encounter because of their experience (Joseph et al., 2020; Remtulla et al., 2012).

Interviewees reported experiencing caring for a sibling as laboursome and challenging. Young sibling carers shared feelings of distress, inner tension, embarrassment, and a perceived lack of control, which may reflect the negative implications of young sibling caregiving that parallels previous sibling caregiving research (Namkung et al., 2017; Reinhard & Horwitz, 1995). Previous studies highlight that young carers feel burdened by caregiving duties, overwhelmed by the nature and level of care tasks, and experience subjective distress (Charles, 2011; Remtulla et al., 2012). Additionally, the challenges and disadvantages that young carers experience to their employment and educational pursuits, as well as to their familial, social, and emotional lives has been highly documented and referred to as the *young carer penalty* (Stamatopoulos, 2018). Heath, psychological, financial, and other costs of being a caregiver are also well documented in the boarder caregiving literature (Montgomery et al., 2007; Schulz & Eden, 2016).

The challenges experienced by interviewees in this study subtly alluded to dominant Western ideals of family roles and relationships and what it means to be 'normal'. While there was no exploration of interviewees' cultural backgrounds in podcast interviews, it may be hypothesized that since they are residents of Ontario, Canada, they have been influenced by Western thought systems. In this way, from a Western perspective, the nuclear family and associated theories encompassing the life cycle are considered the norm, and siblings who take on caregiving roles may experience inner tensions as their lives do not seem align with this perspective (Kramer & Hamilton, 2019).

Another prominent theme in the present study that may align with Western ideals, pertained to social judgment. Interviewees shared their experiences of this through a perceived sense of misunderstanding of their role by society and the protective strategy of censoring information from others to cope with these misrepresentations. Since sibling caregiving is seen as non-normative in Western society (Kramer & Hamilton, 2019), often the interviewees in this study described encountering misperceptions of their roles and responsibilities from their peers. One interviewee, for example, disclosed that they are met with sympathy for having taken on this role, when in their subjective experience there are multiple benefits to being a young sibling carer. Additionally, interviewees' peers did not seem to understand the level and nature of caregiving tasks, which may potentially lead to or exacerbate feelings of social isolation for the young sibling carer. This parallels previous literature that documents how the lack of understanding from friends contributes to young carers being absent from social circles and feeling isolated (Levine et al., 2005; Stamatopoulos, 2018; Szafran et al., 2016). To shield themselves from misrepresentation, interviewees in this study withheld information about their caregiving experiences from peers and authority figures (e.g., teachers). In some cases, this may be a tool to preserve their caregiving identity, and in others, it may align with the idea of keeping their caregiving role a secret from

others. The notion of secrecy has come up in prior literature and used by carers as a means to maintain family solidarity (Szafran et al., 2016) or to avoid potential negative repercussions or social judgment related to their caregiving role (Bolas et al., 2007; Lakman et al., 2017).

Young sibling carers in the present study also felt a need to advocate for their sibling in public settings by confronting the negative attitudes and discriminatory behaviours of others. One interviewee noted that they would engage in verbal altercations with others if others stared or used derogatory language to describe the challenges that their sibling experienced. Feeling a sense of obligation to protect the sibling has been more thoroughly explored in the context of abuse or neglect by parents (Szafran et al., 2016) and less focused on the need to provide protection in public settings. The obligation to protect siblings from negative public perceptions and conduct may be fueled by a willingness to challenge dominant Western ableist discourses surrounding the language used to describe individuals who face physical, mental, or developmental challenges and denouncing ideas of normalcy in people's lives.

Some researchers have found that school seemed to act as a double-edged sword for young sibling carers in that it can feel like an escape from caregiving duties but can also generate a different set of obstacles (e.g., missing school, sleeping in class, receiving poor grades, or being unable to complete homework or participate in extra-curricular activities) (Szafran et al., 2016). Moreover, young carers may find it challenging to be away from their sibling for long periods of time (i.e., during school) and may therefore experience increased distractibility and difficulty focusing in class (Lakman & Chalmers, 2019). In the present study, interviewees did not describe the positive aspects that the school setting provided and mainly disclosed the challenges they faced associated with balancing schoolwork, their social lives, and being a young sibling carer. One reason for this may be due to the lack of awareness and recognition of young carers and subsequent supports implemented in school settings. Lakman et al. (2017) found that if support services were made available in school environments, young carers would often engage with these programs. They further proposed that positive academic outcomes for young carers may be attributed to receiving support services at earlier ages (i.e., in elementary school) and encouraged future researchers to continue to examine this association (Lakman et al., 2017). Connecting young carers with resources through school settings may alleviate some of the pressures they feel when trying to maintain their numerous roles.

Much like other young carer experiences, the interviewees in this study found themselves providing support for their siblings physically, emotionally, and in the form of ensuring optimal skill development. A sense of obligation to provide physical support to the care recipient was noted in this study which parallels general young caregiving research that recognizes a young carers' role in practically or instrumentally supporting others (Lackey & Gates, 2001; Siskowski, 2006). It should be noted that young sibling carers are not limited to carrying out these types of tasks and that the level and nature of their duties are based on the nature of the care recipient's needs (i.e., whether they experience developmental disabilities, mental or physical health challenges, etc.).

Interviewees also reported engaging in emotional support or caring, which included being attuned to the sibling, sacrificing their personal and social experiences to mitigate sibling distress, and worrying about their sibling. This aligns with recent findings by Berardini and colleagues (2021) who describe that young carers are highly compassionate to their loved ones but tend to experience tension and struggles when attending to their own self-care and self-compassion.

Interviewees reflected on the lack of opportunities that their sibling had, which was, for some, accompanied by feelings of guilt and the desire to deprive themselves of positive experiences. These findings parallel previous literature which highlights the greater likelihood of young carers experiencing worry, distress, and feelings of guilt about the care recipient (Becker, 2007; Burke & Montgomery, 2001). A common theme in research on young carers is the experience of social isolation due to not having time to participate in social activities because of their caregiving role (Charles, 2011). However, this study proposes that young sibling carers may intentionally disengage from participating in social commitments due to this heightened sense of guilt and awareness of their sibling's social losses. This parallels Lakman and Chalmer's (2019) research on the young carer profile where it is suggested that higher withdrawal (i.e., a trait of young carers compared to non-carers) leads to a lack of engagement with others and lower quality friendships. Furthermore, the results of Szafran et al.'s (2016) study also note the emotional implications that caring for a sibling had on young sibling carers, and how this acted as a long-lasting repercussion in adulthood (i.e., inability to trust others and make meaningful, positive relationships).

The notion that sibling caring and being responsible for a sibling is 'normal' was prevalent across all podcast interviews, which was brought to light by the ways in which young carers in this study described the historical nature of their caregiving duties. The literature parallels this finding in that it suggests that children are typically socialized into caregiving roles, being unaware that they engage in care *work* (Lackey & Gates, 2001; McGibbon et al., 2018). Smyth et al. (2011) points out that young carers often do not recognize themselves as holding this title because intra-familial bonds of love and reciprocity normalize providing care in family dynamics. When youth are aware of their roles as young carers, they may not feel as though they have a choice in taking on these responsibilities as they often see no other options due to feeling like the care recipient would not be able to manage without them or because it seems like the normative role one would play with loved ones (McDonald et al., 2009; Sprung & Laing, 2017).

Implications

Results from this study have several implications for various stakeholders including healthcare professionals, young sibling carers, and policy makers. The cultural assumption that young people will not engage in caregiving duties if parents are present (Namkung et al., 2017; Smyth et al., 2011) may hinder health care providers from recognizing young carers' own caring needs and challenges. Based on the results of this study and other research, siblings often take on active caregiving roles and should be included in the planning and treatment processes. The inclusion of siblings as recipients of health care may help foster a sense of visibility, which has been lacking in this population, and may enhance the positive implications and protective factors in young sibling caregiving. Moreover, if healthcare professionals were more aware of the role that siblings play in caregiving, they may be more likely to refer these individuals to additional supports and resources that would help alleviate some of the challenges that young sibling carers encounter.

There remains a challenge with respect to accessibility of therapeutic supports, since most

young sibling carers find their time limited and constrained to home and school life. One way to make counseling services accessible to young sibling carers, is through implementing this in school settings. Teachers may consider reducing the amount of homework and implementing flexibility with deadlines to alleviate some of the pressures placed on these youths as they balance multiple roles. More broadly, schools could try to raise awareness of young sibling carers (i.e., through classroom curriculum, information sessions, assemblies, etc.) so that students who are in this role may feel more comfortable, seen, and accepted among their peers, increasing their likelihood of reaching out for support and alleviating caregiver burden.

Young sibling carers may also benefit from the results of this study. This study may draw their awareness to the podcast where they can directly listen to the lived experiences of other young sibling carers. This may help to normalize their experiences of complex and conflicting emotions that arise when in this role, which may foster a sense of connection in that they are not alone in their experiences. While it is difficult to maintain social ties and engage in social activities, young sibling carers who read this research may find it helpful to know that there is a large network of young carers who they can reach out to through online platforms or by contacting The Young Caregivers Association. Having this sense of support may serve as a protective factor along the young sibling caregiving journey. Young sibling caregivers may also feel a sense of hope in that their voices are being heard and shared and that researchers care about their experiences in this role. This may inspire them to continue to be leaders of change and advocate for their rights, and may further serve as a motivation to access the supports that are currently available in Canada.

Through this research and the increasing literature on young carers in Canada more generally, it is hoped that policy makers and governmental organizations can recognize the importance of ensuring that this population is properly supported. These institutions may consider increasing funding for counseling, schools, and research.

Limitations

Although this study garnered insight on interviewees' experiences of being young sibling caregivers, there are some limitations that warrant acknowledgment. Firstly, since the data were collected from previously recorded online podcasts, we did not have the opportunity to engage with interviewees directly nor follow up with them. Similarly, it was not possible to directly ask interviewees about their caregiving experiences in greater detail, nor check if our interpretations aligned with their understandings. Secondly, interviewees may have felt a sense of pressure to overreport positive emotions and attenuate more negative emotions surrounding their role as young sibling carers due to social desirability or cultural misrepresentations that overemphasize negative aspects of caregiving. On the other hand, interviewees may have felt the need to report negative emotions due to feelings of pressure to assimilate to the more negative dominant sociocultural ideas about young caregiving. Thirdly, while the results may be applicable to other young carers and settings, readers must note that the results of this study should be interpreted with caution, as they are limited to young sibling caregivers who provide care for siblings with an illness and/or disability, as opposed to those who do not face health challenges (e.g., providing care while parents are absent). Fourth, the lack of clarity regarding interviewees' social positioning is a limitation of

this study, because broader sibling caregiving literature reflects that gender and other markers of socio-cultural diversity play a role in sibling caregiving experiences (Namkung et al., 2017). Finally, it should be acknowledged that podcasts were recorded prior to the COVID-19 pandemic, which has had an impact on the nature of caregiving, the amount of caregiving duties, feelings of isolation, and supports available during this time for young carers throughout the world (Blake-Holmes, 2020; Carers Trust Scotland, 2020; Carers Trust UK, 2020; Carers Trust Wales, 2020; Martin, 2021; Wylie-Curia, 2021).

Future Directions

Researchers may consider implementing a longitudinal research design to better understand how young sibling carers' meaning making experiences change or remain the same over time. Doing so may contribute to structuring resources and supports around the developmental age stages of this population since there are different conceptualizations of caregiving as one matures. Additionally, young sibling carers who are at different age stages may have various additional personal responsibilities (i.e., school and/or career pursuits, romantic relationships, etc.) and may find themselves requiring fluctuating levels of support in unique areas of their lives. Given that gender, race, class, etc. of interviewees were not discussed in interview podcasts, future research should also qualitatively examine experiences of diverse young carers to gain a deeper, variable, or more nuanced understanding of what it may mean to care for a sibling. This may have implications for *which* young sibling carers feel particularly burdened by this experience due to their social positioning and highlight which populations need greater support and more accessible resources since those who experience intersecting inequalities face increased marginalization of their care work (Alexander, 2021).

Conclusion

The research herein explored how young Canadian sibling caregivers living in Ontario make sense of their caregiving experiences. It is evident that young sibling carers' experiences encompass a wide variety of mixed emotions and challenges, as well as a sense of resilience and perseverance. It is critical that macro-level organizations (e.g., governmental agencies, policy makers, institutions) play a role in raising awareness for this population and that they continue to enforce accessible resources and supports that mitigate caregiver burden and enhance the wellbeing of young carers.

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