

The Experiences of Young Sibling Caregivers in Ontario: A Qualitative Study

by

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ABSTRACT

THE EXPERIENCES OF YOUNG SIBLING CAREGIVERS IN ONTARIO: A QUALITATIVE STUDY

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This thesis explored how young sibling carers living in Ontario, Canada make sense of their caregiving experiences. Data was obtained from an interview-style podcast 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. Results suggest that young carers experience a sense of obligation and responsibility to fulfill this role among the other roles they hold in their lives. A feeling of normalcy due to the age at which participants began taking on this role was evident across podcast interview responses. 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.

DEDICATION

This thesis is dedicated to my mother, Angela Iacobucci, whose selflessness, courage, and strength has guided me through all of my academic endeavors and inspired me to never give up. Mom, this accomplishment is just as much yours as it is mine- I hope I've made you proud.

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Introduction

The sibling relationship is 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; Goetting, 1986). In addition, the sibling relationship impacts the formation of siblings' identity, self-esteem, and adjustment (Brody, 1998; Cicirelli, 1995; Dunn, 1992, 1993; Shantz & Hartup, 1992; Yeh & Lempers, 2004). Due to the intricate nature of this bond, siblings often turn to one another in times of need by providing care to each other.

In some cases, siblings may offer care as an extension of values learned from within the family, portrayed as more of an instinctive and subtle act, and in other instances, sibling caregiving may be a necessity in order to maintain a sense of homeostasis within the family particularly in situations where there is illness, disability, and/or absent parents (i.e., due to work commitments, providing care for their aging parents, facing hospitalization, etc.)(Willyard et al., 2008). In both circumstances, there are various duties that one may take on in their role of sibling caregiver such as, providing emotional and social security, physical assistance, and instrumental support (Boll et al., 2003; Whiteman et al., 2011; Yeh & Lempers, 2004). As a result of the nature of care tasks combined with the time allocated to caregiving, both negative and positive outcomes of have been documented. For example, negative impacts of sibling caregiving reported in the literature include distress, guilt, isolation, restriction of educational opportunities, financial challenges, and feeling burdened and overwhelmed by caregiving responsibilities (Horwitz & Reinhard, 1995; Namkung et al., 2017; Remtulla et al., 2012). Moreover, the *young carer penalty*, a term built off of the conceptualization of the gendered care penalty in adult

women (England & Folbre, 1999), encompasses the challenges and disadvantages that young carers experience to their employment and educational pursuits, as well as to their familial, social, and emotional lives (Stamatopoulos, 2018). Researchers have also identified positive impacts of sibling caregiving; these include resilience, higher levels of maturity, self-efficacy, closer family relationships (i.e., particularly with the recipient of care), and competence (Charles, 2011; Remtulla et al., 2012; Szafran et al., 2016). In addition, Stamatopoulos (2018) found that young carers felt a sense of pride, competence, empathy and compassion, and acknowledged that positive changes to their life priorities and future goals resulted from their caregiving experiences.

The number of young carers in Canada has increased in the last two decades. Chadi and Stamatopoulos (2017) reported that in 2006, data from Statistics Canada revealed that approximately 1.18 million youth between the ages of 15-24 years old provided some level of unpaid care to family members, which reflected a 13.5% increase from 1996. Ontario experienced the greatest leap of 27.5% compared to the other Canadian provinces, which highlights that increased attention to this population is warranted (Chadi & Stamatopoulos, 2017). Within the population of young carers in Canada, research reveals that 45,356 of them provided 30 or more hours of care to children (i.e., siblings or other children in extended family networks) (Stamatopoulos, 2015). According to a 2007 global analysis characterizing national levels of youth carer awareness and policy response, there has been an increase in research, services, and programs in place for young carers in the United Kingdom, Australia, and United States (Stamatopoulos, 2016). Canada has been slower than some of these other countries in recognizing and addressing this issue, as evidenced by nearly non-existent legislative supports, funding, and integration within schoolboards, potentially making young caregiving a more

pressing issue for this country (Stamatopoulos, 2016). The invisibility and lack of understanding of this population by the general public, social and governmental services, healthcare professionals, and therapists, have left many young carers feeling isolated, and increases their probability of experiencing future negative consequences as a result of young caregiving (Charles et al., 2008). Due to this lack of awareness, few programs and/or services have been established to support the unique needs of young sibling caregivers in Canada (Stamatopoulos, 2015), which suggests that further exploration of this research issue is warranted. The present literature on sibling caregiving has been part of existing research on young carers in Canada (Stamatopoulos, 2015, 2016, 2018), however few studies have focused exclusively on siblings as caregivers. Of the research that does exist, attention is given mainly to siblings in adulthood and older adulthood and the few studies that have focused on young sibling caregivers' experiences of caregiving in Canada are often retrospective accounts and may be subject to recall bias (Rose & Cohen, 2010; Szafran, et al., 2016). Moreover, this population of young carers experiences 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. To address this gap, the current study sought to qualitatively explore how young Canadians under the age of 25 make sense of their present experiences of caring for their siblings. It is hoped that the study will capture the attention of society, government and policy-makers, social service agencies, and healthcare professionals to create policies, programs, and services to support young caregivers.

Literature Review

This section will provide the reader with background information on caregiving literature before honing in on young sibling carers in Canada. The purpose of this is to orient the reader by first making sense of general caregiving and sibling caregiving, followed by a review of the

research on young caregivers, and finally focusing on young sibling carers in Canada. The section will close with a comparison of how the broader caregiving research (i.e., including adult sibling caregiving) both parallels and differs from that of young sibling caregiving in Canada.

Caregiving

There is no uniform definition of “caregiving” in the family context, as family members understand themselves as caregivers in various ways and may execute a range of tasks and accomplish them in a variety of ways (Barg et al., 2014). Pearlin et al. (1990) highlighted the notion that there are differences between informal caregiving, caring, and caregiving. They suggest that informal caregiving relates to the activities and experiences involved in offering assistance to relatives or friends who cannot care for themselves. Caring, in contrast, is the affective state of concern for another’s well-being. Finally, caregiving is the behavioural manifestation of this concern (Pearlin et al., 1990). In this way, all close relationships contain caregivers since it is believed that providing care is an expansion of feeling care or concern for another.

When considering the role of caregivers in familial relationships, it has been argued that typically one family member acts as the primary caregiver and other individuals in the family dynamic may take on secondary caregiving roles (Montgomery et al., 2007). Broadly, the primary caregiver tends to be the one who has the least competing responsibilities and as such, is often most available to allocate themselves and their time to caregiving duties (Brody, 1990; Stern, 1996; Stueve & O’Donnell, 1989). However, it is also important to note that these individuals often must shift their responsibilities and the division of labour within the home over time in order to make room for caregiving duties, since caregiving does not occur in isolation from other responsibilities and engagements (e.g., parental, child, sibling, employment,

community, etc) (Schulz & Eden, 2016). Literature on familial caregiving was brought to light by changes in the function and structure of the family including, but not limited to, reduced family size, fluctuating family roles (e.g., more women in the workforce), increased life expectancy of older populations due to medical advancements, and shifting gender roles in the provision of care (Karantzas, 2012).

Historically, familial caregiving has been characterized as the emotional, instrumental, physical, financial, and social support family members provide on a regular or occasional basis (National Family Caregivers Association, 1998). Caregiving tasks have been defined as assisting with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), such as bathing, dressing, cooking, providing medication, washroom duties, shopping, going to appointments, and others (Albert, 1991; Barg et al., 2014). Several factors go into assigning and maintaining caregiving activities which include, but are not limited to, the type of impairment, location of caregiving, patient competency, the ability to access resources, and the ability to negotiate with the healthcare system (Barg et al., 2014; Schulz & Czaja, 2018). Research has shown that family caregivers felt most successful in providing care when it was tailored to the behaviours, temperaments, characteristics, and traits of the individuals providing care (Schumacher et al., 2000). This suggests that feeling a sense of accomplishment in offering family caregiving services may be due to factors beyond following medical orders and providing functional assistance (Barg et al., 2014), which is in line with the present view of caregiving whereby this process is also influenced by emotional and psychological elements. Typically, most families are not prepared to take on caregiving duties and they do not have an idea of what constitutes providing full-fledged care for another, yet they willingly take on these roles (Barg et al., 2014). However, in cases where young carers begin providing care from an early age (e.g.,

young sibling caregivers), they may look to older family members to learn these roles and responsibilities (Barg et al., 2014). Family members usually begin caregiving by assisting with tasks such as transportation, shopping, hygiene, dressing, or nourishment, and progressively, more duties are undertaken until all needs are met by the care seeker (Barg et al., 2014). In cases where caregiving occurs as a result of a sudden medical illness (e.g. stroke, heart attack, etc.), these tasks are typically taken on in a shorter period of time and acute adaptations are required in order to support the loved one (White et al., 2014).

Caregiving has been viewed as a life-changing task because those who provide extensive care for loved ones may choose to transform their lives by altering their lifestyles, leave their jobs, and part from their social lives (Barg et al., 2014). Moreover, taking on the role of caregiver leads to a change in one's personal identity, which can take place over time or fairly quickly and most often leads to feelings of inner tension and distress. Montgomery et al. (2007) described this process as occurring over five stages, when considering adults caring for their elderly parents. In the initial stage, family members may not recognize themselves as caregivers as they engage in caring activities that are typical of their familial role. In the second stage, the caregiver becomes more aware that their duties extend beyond those of what they normally would provide for a family members, and it is believed that at this point self-identification as a caregiver ensues (Montgomery & Kosloski, 2000a). In phase three, the caregiver is conflicted between upholding their personal identity as a family member versus a primary identity as a caregiver, because the needs of the care recipient increase substantially in quantity and intensity. The fourth and fifth stages represent the caregiver considering and then placing the care recipient into assisted living arrangements to alleviate them of primary care responsibilities. It should be noted that this process is not identical for all familial caregivers, and the experience of caregiving is not

universal, as there are multiple factors involved. Similarly, Schulz and Eden (2016) described the process of recognizing oneself as a familial caregiver through the caregiving trajectory, which recognizes that being in this role is fluid over time and can encompass different phases. They described these phases as awareness, unfolding responsibility, increasing care demands, and end of life. For these reasons, these individuals often experience emotional and psychological consequences resulting from their caregiving role. The notion of *role strain*, that is, taking on multiple roles and responsibilities that leads to negative effects on one's well-being (Goode, 1960) has been used to describe the adverse psychological and other impacts of caring on familial caregiving (Lee & Tang, 2015).

Forms of Caregiving

The nature of caregiving tasks differs among familial carers as these tasks require complex and varying degrees of emotional and physical investment. For example, the duties caregivers engage in, how they complete them, and the length of time they participate in caregiving is not universal. Montgomery et al. (2007) posited that the closeness of the familial relationship is associated with the amount, type, and continuity of care provided. That is, those who are more closely related to the care recipient would provide greater amounts of care, both in quantity and intensity. Family caregivers may find themselves arranging and attending medical appointments, joining in treatment decisions, coordinating care and services, helping with ADLs, ensuring basic human needs (i.e., food and shelter) are met, and managing finances (Schulz & Czaja, 2018). Moreover, they may take on household tasks, self-care, supervision, and mobility of the care recipient, provide emotional and social support, encourage health and medical care, and participate in advocacy and care coordination (Schulz & Eden, 2016).

Outcomes of Caregiving

Pearlin et al. (1990) highlighted that the outcomes of familial caregiving may be guided by the stress model. This model encompasses four domains that make up the stress process: the background and context of the stress (i.e., characteristics of the caregiver, relationship between caregiver and care recipient, social and service delivery of care); the primary stressors (i.e., care recipient's level of cognition, challenging behaviours, and need for assistance with ADLs); secondary stressors (i.e., restricted social, occupational, and recreational activities and intrapsychic constraints); the mediators of the stress (e.g. coping and social support); and the outcomes or manifestations of the stress (i.e., changes in the caregiver's mental and physical health) (Montgomery et al., 2007; Pearlin et al., 1990).

The literature highlights some of the negative implications of caregiving, including infringement on carer's time and activities, changed relationship with the care recipient, impacts to physical and mental health (i.e., depression, anxiety, limited self-care), social isolation, disruption of other family responsibilities, and financial challenges (Montgomery et al., 2007; Schulz & Czaja, 2018). Moreover, much of the research on caregiving has focused on caregiver burden, which is defined as the negative physical, psychological, emotional, social, and/or financial implications of caregiving (Chappell et al., 2014). The stressors of caregiving that may lead to caregiver burden include, but are not limited to, depression, guilt, worry, anxiety, loneliness, emotional strain, and physical and social functioning limitations (Bastawrous, 2013). Caregivers may experience feelings of loss in conjunction with feelings of reward, feelings of restriction entangled with a sense of authority, and a sense of helplessness paired with feelings of inner strength (Barg et al., 2014). Caregivers are often subject to feelings of depression and anxiety due to presenting feelings of sadness and/or anger for the loss of their life and the loss of the person they are caring for, anger and resentment for caring for someone who may or may not

have previously wronged them, and anger and defeat for feeling stuck in a hopeless circumstance (Barg et al., 2014; Chappell et al., 2014; Penning & Wu, 2015). Additionally, caregivers may experience feelings of worry, guilt, and an overwhelming feeling of responsibility due to a sense of obligation to care for a loved one, which may be heightened if there are minimal to no improvements in their conditions (Barg et al., 2014).

A large portion of caregivers may also recognize positives resulting from their role as a carer. One way this has been evidenced is through the idea of role enhancement, which posits that individuals benefit from holding multiple roles (Sieber, 1974). Some individuals feel as though they have the capacity to balance differing roles with success, leading to feelings of pride. Others may perceive one of their roles to be burdensome (e.g., caregiving) and compensate for this in their other roles, alleviating some of their perceived losses or feelings of distress (Saunders, 2010). For example, Noonan and Tennstedt (1997) revealed that caregivers who can find meaning in their caregiving identities experience higher levels of self-esteem and lower levels of depression. Additionally, it has been reported that caregivers feel a sense of pride and accomplishment in gaining the ability to manage caregiving roles in tandem with their own lives. Furthermore, many caregivers have reflected on the new skills they gained as a result of caregiving, others feel a sense of gratitude for being able to reciprocate care and support, and some feel that the experience of caregiving provides them with an additional sense of purpose in their lives (Barg et al., 2014). Overall, feeling a heightened sense of mastery, positive affect, and a strengthened relationship between the caregiver and care receiver are common positive outcomes of familial caregiving (Montgomery et al., 2009).

Motivations Underlying Caregiving

Karantzas (2012) suggested that there are two prominent incentives for familial caregiving: obligatory motives (i.e., a sense of obligation to care) and discretionary motives (i.e., a desire to care based on attachment). Obligatory motives have been described as central to caregiving because they are enmeshed in cultural and family-based customs of family functioning (Dilworth-Anderson et al., 2002). Discretionary motives may be observed through attachment by means of safeguarding and protecting familial bonds (Karantzas, 2012). Indeed, the historical bonds created between caregiver and care recipient prior to caretaking have implications for the caregiver's feelings of desire to provide care which may be based on attachment security and insecurity, a discussion that is beyond the scope of this research paper. Depending on the closeness of care recipient and care provider (i.e., spouse, children, extended family), there are differences in the degree to which one feels a sense of obligation and desire to provide care (Chumbler et al., 2003). For example, those who are part of an extended family network (i.e., aunt or uncle) may feel less responsibility than one who is more closely tied to the recipient of care (i.e., spouse).

Sibling Caregiving

The topic of siblings as caregivers is limited in the current literature and is often is described as the emergence of secondary caregiving when parents can no longer provide care for their child and/or alongside parents who act as the primary caregivers (Lakman & Chalmers, 2019; Namkung, 2017). The relevance of studying sibling caregivers is two-fold. Firstly, with advancements in the medical and social support fields, children who have life-long disabilities now have increased longevity and may outlive their parents who act as primary caregivers (Namkung et al., 2017). In this scenario, well siblings may begin to take on caregiving roles from an early age, alongside parents, in an attempt to familiarize themselves with their potential future

caregiving duties. Secondly, changes in marital patterns of baby boomers have been noted which accounts for higher rates of divorce and fewer marriages, and therefore may place siblings in less commonly occupied roles, including that of a caregiver to their siblings (Namkung et al., 2017).

The findings regarding burden for siblings who act as caregivers appear to be mixed. Siblings may experience negative consequences of caregiving for their brother or sister because typically, they would not assume this role (Szafran et al., 2016). As a result, siblings may provide less caregiving assistance while experiencing greater levels of stress due to the inner tensions that result from balancing being presented with caregiving responsibilities and unwanted feelings of obligation to engage with them (Reinhard & Horwitz, 1995). Sibling caregivers may also experience feelings of embarrassment, guilt, and neglect by parents and mental health and healthcare systems. Healthcare professionals may fail to involve siblings in a patient'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 sibling caregivers to non-caregiving siblings, research reveals that caregivers experience more depressive symptoms, poor perceived 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). This may either be part of the reason why they took on the caregiving role originally, or it may be that most of their time is spent caregiving and less time is spent dedicated to tending to their personal lives. Moreover, given the nature of sibling bonds, the 'well-sibling' may experience ambiguous loss, leading to feelings of grief that they are constantly reminded of due to their caregiving responsibilities (Abrams, 2009). It has been speculated that by adulthood, sibling caregivers have additional demands including

competing work and family obligations, and the additional pressure to provide care for a brother or sister can be physically, emotionally, and financially draining (Namkung et al., 2017).

Interestingly, when comparing sibling caregivers to other family caregivers (i.e., parents, adult children, spouses) a different pattern emerges. Viana et al. (2013) found that siblings who acted as caregivers for their brother or sister that had chronic physical and mental health conditions reported fewer burdens than caregivers of spouses, children, or parents. Consistent with this finding is that of Penning and Wu's study (2015), which highlighted that sibling caregiving was correlated with lower levels of stress and more positive mental health when compared with spouse or child caregivers among middle- and older-age samples of caregivers. Furthermore, Shahly et al. (2013) illustrated that spouse and parent caregivers described greater levels of burden than siblings and adult-child caregivers. Reasons for these findings may be because as siblings age, they are less likely to live with one another and therefore encounter fewer problem behaviours that caregivers find burdensome (Namkung et al., 2017). Moreover, there is the notion that siblings may feel as though they have a choice in taking on a caregiving role, more so than parents, adult children, or spouses do.

Sibling Caregiving and Sibling Relationship

Relationships between siblings are one of the most long-lasting relationships throughout the lifespan (Park & Lee, 2017). Unlike other social relationships, sibling relationships encompass hierarchy (e.g., birth order) and reciprocity (e.g., mutual dependency). As siblings grow from childhood to late adulthood, their hierarchical and reciprocal positions, roles, needs, and relationship quality may vary (i.e., structurally and functionally) (Whiteman et al., 2011), which may be associated with the tendency to take on caregiving duties.

Much of the research done on sibling relationships is informed by theory, which has been examined through various stages of the life course. Some theorists have focused on specific periods (i.e., childhood, adolescence, adulthood), while others described the sibling relationship throughout the life course. The most common theories that inform the study of sibling relationships include psychoanalytic-evolutionary, social-psychological, social learning, family systems, and ecological. I will briefly discuss relevant aspects of attachment theory (Bowlby, 1969) and ecological systems theory (Bronfenbrenner, 1979, 1986, 2005); however, it should be noted that in the present study, analysis will primarily be guided by ecological systems theory (Bronfenbrenner, 1979, 1986, 2005).

Attachment theory (Bowlby, 1969) may help to explain the relationship between sibling bonds and caregiving, as this theory focuses on the developmental changes in social relationships which are strongly tied to early bonding experiences. As children familiarize themselves with their social environments, they often turn to their siblings for emotional security, as well as to understand relationships, expectations, and behaviours, which may strengthen their attachment to one another (Whiteman et al., 2011). Sibling bonds may continue throughout the lifetime (Van Volkom, 2006) and it is therefore hypothesized that siblings who form closer attachments in childhood may be more likely to take on caregiving obligations. In some cases, older siblings may be positioned as the attachment figure for younger siblings (i.e., if the primary caregiver is unavailable, such as during marital conflict, etc.) (Whiteman et al., 2011), instinctively subjecting them to caregiving tendencies.

In the adolescent period, the nature of attachment between siblings may change due to the unique developmental transitions, tasks, and problems that present. During this period, siblings may serve as an essential source of social support to assist their adolescent sibling with

overcoming such obstacles and distress (Yeh & Lempers, 2004), which may further reinforce their attachment, contributing to features of caregiving. It has been hypothesized that secure attachment to siblings and positive internal representations of strong sibling relationships in adolescence may contribute to successful social development during this period (Yeh & Lempers, 2004), which may heighten caregiving characteristics. For example, siblings who are close to one another are more likely to identify with each other and to serve as dependable support networks offering help and advice about personal issues (Cicirelli, 1995). Additionally, Amato (1989) discovered that close siblings acted as models and regulators to assist adolescents with following rules and standards set by larger institutions, and provided them with the opportunity to mirror acceptable social skills and desirable social behaviours. The preceding examples highlight the qualities in siblings (e.g., dependable, supportive, helpful, advisor, models) that may form the susceptibility to act as a caregiver. It may be assumed that representations of attachment in childhood and adolescence influence how siblings interact with each other and perceive support in their relationships as they enter into early adulthood (Fortuna et al., 2011), fostering a safe and reciprocal foundation for caregiving to ensue if necessary.

As siblings transition from adolescence to early adulthood, their relationship becomes voluntary, and as a result, it is common for siblings to decrease their contact with one another as they experience new life changes, pursue new friendships, develop romantic interests, move away from home, and join the workforce (Whiteman et al., 2011). Nonetheless, research has revealed that as siblings enter into adulthood and older adulthood, the sibling bond restrengthens, which appears as an increase in social support (i.e., from adolescence/early adulthood), contact with one another, and emotional and physical assistance, especially if one sibling is compromised in some way (e.g., widowed or ill). This may account for part of the reason why

siblings at this age stage tend to rely on one another more frequently (i.e., provide care for one another), creating a sense of normalcy around sibling caregiving that occurs during this period.

Bronfenbrenner's (1979, 1986, 2005) ecological systems theory proposes that there are many levels of contextual influence on one's development and these levels of influence are highly tied to sibling relationships (Whiteman et al., 2011). This perspective focuses on the various levels of influence described as nested systems (Bronfenbrenner, 2001) that include, the microsystem, mesosystem, exosystem, macrosystem, and chronosystem, which may shed light on direct and indirect influences that guide sibling caregiving. Encompassed within one's microsystem are the immediate everyday life contacts such as family members. At the level of the microsystem, supportive sibling relationships and influences on one another present, as do the distinctions of activities and roles for siblings based on their age and gender (Whiteman et al., 2011). Within the mesosystem are the connections formed between and within the microsystem. Here, norms concerning age and gender may surface, as siblings move outside of their family homes and learn how to behave towards one another in different settings (i.e., outside of the family) (Whiteman et al., 2011). The exosystem indirectly impacts sibling relationships due to overcoming the obstacles that present in the microsystem. For example, sibling caregiving may occur if parents are working long hours and cannot perform typical parenting duties (i.e., making dinner, bathing young children, etc.) (Whiteman et al., 2011). The macrosystem involves the broader socio-cultural, economic, and political forces that underlie behaviours, roles, and attitudes in sibling relationships and young sibling caregiving. Finally, the chronosystem encompasses a temporal element by considering how interactions between systems impact each other over time (Bronfenbrenner, 2001). Research with racialized and minoritized families in the United States emphasizes the role of cultural values and experiences in

influencing sibling relationships. For example, in a study with Mexican American adolescent siblings, it was discovered that one's sense of family obligations (i.e., familism) is associated with more intimate sibling relationships (McHale et al., 2005; Updegraff et al., 2005), which may entice a sibling to take on caregiving responsibilities. Moreover, cross-cultural research has highlighted the normative caregiving responsibilities placed on older siblings, as well as the hierarchical organization of sibling roles and norms in non-Western societies (Maynard, 2004; Weisner, 1993; Zukow, 1989).

Young Caregivers

The age range that encompasses the definition of being a young carer has been highly debated. For this study, a young sibling carer refers to an individual under the age of 25 years old who takes on responsibilities beyond the normative expectations given their culture, ethnicity, and age (Chadi & Stamatopoulos, 2017; Charles, 2011; Stamatopoulos, 2016, 2018). There are several reasons why youth may fall into the role of caregiver to a family member. Research has highlighted that in the United Kingdom (UK) more than half of young carers live in one-parent families, which increases their need for being an active caregiver (Becker & Dearden, 2005). Typically, the types of support these young caregivers provide involve domestic work, general care, emotional support, intimate care, child care, and other household and administration tasks including, but not limited to, paying bills, translating, and accompanying family members to hospital visits when the family member has an illness, addiction, or disability (Becker & Dearden, 2005; Charles, 2011).

One may hypothesize that young caregivers face greater challenges to their psychosocial, emotional, and cognitive development, have limited opportunities to participate in academic, peer, and social activities, and to pursue employment prospects compared to older caregivers and

their non-caregiving peers, making their transition into adulthood more challenging (Becker & Dearden, 2005; Remtulla et al., 2012). Feelings of distress, guilt, isolation, worries about being skillful and competent enough to provide care, being burdened by caring responsibilities and overwhelmed by the nature and level of care tasks have been frequently described in the literature (Charles, 2011; Remtulla et al., 2012). For example, a study in Southern Ontario observed that young carers spend 7-27 hours per week participating in caregiving duties including, but not limited to, undertaking domestic tasks, caring for children, intimate/personal care, emotional/mental support, and medicine/nursing care, compared to non-caregivers who spend approximately 2 hours per week helping out around the home (Lakman et al., 2017). These youths provided care for family members who were ill, disabled, depended on substances and/or alcohol, or for those who had language barriers. The researchers also found correlations between time spent caregiving and absence from school, as well as limited future aspirations (Lakman et al., 2017). Charles (2011) also reported that additional negative consequences experienced by young caregivers include feelings of not being in control of their lives, physical injuries from carrying ill or intoxicated family members, self-harm, substance misuse, mental health concerns, and missing school for extended periods of time. Moreover, the increased maturity of young carers as well as the lack of time they can afford to participate in their personal social lives may lead to feelings of social isolation (Charles, 2011). This in turn, along with the fact that young caregivers may experience stigma related to reasons why they must provide care (i.e., stigma regarding the condition of family members), may cause young caregivers to experience feelings of anger and depressive symptoms, further removing them from peer relationships (Charles, 2011). A retrospective study that interviewed older adults who reported being young caregivers highlighted that negative outcomes of caregiving which increased their struggles later in life was

due to the expectation of them to be an adult in their families, being dehumanized by their caregiving experience, being forced into parentified relationships, and/or experiencing a lack of reciprocity in their interactions (Charles et al., 2010). Additionally, the coping strategies employed at this age may not be the most positive ones. For example, some older adults who were once young carers reported that in order to not feel distress, they would ‘act out’, engage in illegal and troubling activities, and engaged in self-injury or behaviours that harmed others (Szafran et al., 2016).

The positive implications resulting from young caregiving are quite consistent across the literature. Young caregivers report feeling higher levels of maturity, a sense of purposefulness, worthiness, selflessness, and importance, self-efficacy, confidence and competence as a result of fulfilling this role (Remtulla et al., 2012; Szafran et al., 2016). Retrospective accounts of older adults who were once young caregivers reported that they learned the skill of problem-solving at a young age and gained a sense of community responsibility which had positive impacts on their futures and in some cases, even motivated their career choices (Szafran et al., 2016). Moreover, they highlight that caregiving impacted the positive relationships and strong emotional bonds formed (i.e., or strengthened) with family members, namely with the recipient of their care (Charles, 2011; Remtulla et al., 2012; Szafran et al., 2016). Charles (2011) found that a significant predictor of positive outcomes resulting from young caregiving has to do with the support and guidance one receives while taking on this role. Therefore, if a young carer does not receive support from friends, other family members, schools, or other facilities geared specifically to their experiences, they may experience greater negative long term outcomes including, but not limited to, mental health issues, addictions, relationship issues, and limited career prospects (Charles, 2011).

Young Sibling Caregivers in Canada

The existing literature on sibling caregiving focuses mainly on siblings in adulthood and older adulthood, and less frequently younger sibling caregivers. Research has revealed that there are more than 185,000 young carers in Canada, aged 15-24 who provide 15 hours or more of unpaid caregiving to those who have long term illness, disability, mental health challenges, substance use issues, or problems related to ageing (Chadi & Stamatopoulos, 2017; Stamatopoulos, 2016). According to a 2007 global analysis characterizing national levels of youth carer awareness and policy response, there has been an increase in research, services, and programs in place for young carers in the UK, Australia, and the United States. However, Canada's lack of nationwide cognizance on this issue, as well as its nearly non-existent legislative supports, funding, and integration within schoolboards, make young caregiving, and by extension young sibling caregiving, a more pressing issue for this country (Stamatopoulos, 2016).

Much of the research has illustrated that young sibling caregivers take on this role to assist their parents when they have their own illnesses, face substance-/alcohol-use related disorders, or are simply absent from family life due to work and/or other social commitments (Stamatopoulos, 2015). However, in some families, the act of caregiving may be seen as a typical family responsibility, and therefore parents need-not experience challenges to their level of functioning when a young sibling carer steps in to fulfill these duties. Szafran et al. (2016) found that the ways in which young carers in Alberta provided care for their younger siblings were by ensuring they were fed, that they attended school, that they completed homework, and that they were well-behaved. The sibling caregivers from this study also reported feeling as though they were depended on by younger siblings, and that they felt as though they needed to

protect their siblings from abusive and/or neglectful parents, and the rest of society (Szafran et al., 2016). Interestingly, they also shared that they chose to keep their caregiving circumstances private in order to maintain solidarity within the family and to prevent feelings of betrayal from surfacing (Szafran et al., 2016). Consistent with these findings is Barry's (2011) work which highlights that young sibling caregivers felt as though they wanted to keep their academic life separate from their lives as caregivers. Several respondents in this study described that they would intentionally hide the fact that they were young sibling caregivers for fear of being treated differently (i.e., preferential treatment or harsh treatment) (Barry, 2011). Interestingly, these individuals also reported that they experienced distress from being placed in the caregiving role within the family, as well as being an adolescent who had a sibling affected by an illness or disability. It is speculated that these negative consequences of young sibling caregiving may be due to dominant Western perspectives held by many Canadian households. However, a positive theme presented in this study was that taking on this role of sibling caregiver felt less like a chore and more of a willingness to do so (Barry, 2011). This may speak to the cultural expectations of siblings as caregivers or may relate to the bonds between siblings and the reciprocal duty to care for one another in times of need. Additionally, attending school seemed to provide a sense of social closeness to their peers, as this was one environment where they could rid themselves of their caregiving obligations and connect with their friends (i.e., a safe haven) (Barry, 2011).

While there have been more recent advancements in generating awareness of young Canadian carers, there are very few services tailored to the needs of young sibling caregivers (Szafran et al., 2016). To implement greater change, it is required that researchers begin to elucidate the meanings of sibling caregiving experiences across an array of illnesses or disabilities, given that the present literature on general young caregiving, largely focuses on

caring for someone who experiences mental or physical health challenges more broadly. In this way, resources for young sibling carers may be better geared to their specific needs (i.e., social, emotional) and the unique experiences carers may have. Moreover, understanding how siblings understand and experience caregiving is required in order to be able to provide greater support. It is believed that exploring this unique issue will be essential to further our knowledge and understanding of sibling relationships and family dynamics.

Comparing Young Sibling Carers with Adult Sibling Carers

Positive and negative repercussions of young sibling caregiving parallel findings from general young caregiving and sibling caregiving literature in that some individuals in this cohort also experience significant distress and burden to their psychological and social well-being (e.g. *role strain*), struggles with feelings of accomplishment, independence, and maturity (Barry, 2011; Stamatopoulos, 2016; Szafran et al., 2016). Similar to the caregiving tasks of adult sibling carers, retrospective accounts of young sibling carers reflected that this population may be responsible for maintaining household duties, supervising their sibling, providing physical, emotional, and social support, encouraging health and medical care, and participating in advocacy for their sibling (Szafran et al., 2016). Differences lie in the fact that these individuals may be at a younger stage in development when they assume the role of sibling caregiver, which may lead to complications in future relationship dynamics whereby they find themselves in compulsive caregiving situations (i.e., assume the caregiver role in all relationships). The notion of compulsive caregiving stems from parentification (i.e., sibling-focused) which has been more widely studied in young sibling caregivers who have a sibling with autism spectrum disorder (Nuttall et al., 2018). Moreover, based on the literature on young carers in general, it may be assumed that young sibling caregivers' educational and career pursuits may be disrupted at this

age stage due to their need to care for their sibling, creating inner tension and feelings of a lack of control of their own lives (Stamatopoulos, 2016). Additional negative implications specific to young sibling caregivers was brought to light through a study on caring for a sibling with schizophrenia which highlighted that young sibling fear what caregiving may look like in the future as they pursue their own paths and if they will even have the opportunity to have a life of their own that is not defined by caregiving for their sibling (Park & Lee, 2017). The authors of this study also found that young sibling carers who provide support to a sibling with a genetic medical condition may worry about developing the illness or disorder themselves (Park & Lee, 2017). Furthermore, it may be hypothesized that young siblings may be more likely to experience a greater sense of responsibility to provide care given the close nature of the relationship in childhood compared to adulthood, and as they age, their relationship becomes voluntary, thereby decreasing feelings of inner pressure and the sense of obligation to act as a sibling caregiver (Whiteman et al., 2011).

Rationale for the Study

The 1.18 million youth in Canada (Chadi & Stamatopoulos, 2017) between the ages of 15-24 years who provide unpaid caregiving to family members is increasing and is expected to continue to increase due to Canada's ageing population, a growing proportion of care required by Canadians with long-term health challenges, women's increased employment, the reduction of social policies permitting early retirement, and an increase in extended family members cohabiting with one another (e.g., grandparents living with grandchildren and vice versa) to ease the financial burden of housing (Armstrong & Armstrong, 2005; Chadi & Stamatopoulos, 2017; Stamatopoulos, 2016). The lack of awareness of young carers in Canada, as compared to the United Kingdom, Australia, and the United States, has deemed them as an "invisible population"

(Charles et al., 2008, p. 5). As a result, legislative supports, funding, and integration within school boards, have not attended to the needs of this population, making young caregiving a more pressing issue for this country (Stamatopoulos, 2016). Moreover, the lack of understanding of this population by society, social and governmental services, healthcare professionals, and therapists may have potentially left young carers feeling isolated and increased the likelihood of them being negatively impacted by caregiving (Charles et al., 2008).

Additionally, the qualitative studies that have been done with young carers often do not focus on who the care recipients are, nor do they highlight any unique differences that may arise from caring for a sibling. As a result, young sibling carers' experiences tend to be generalized into the larger population of young carers and do not yet have their own distinct body of literature. 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) found that young sibling carers tend to worry about their likelihood of developing the same illness or disorder as their sibling, what their futures look like, and if they will be able to pursue their own paths in a way that is not defined by caring for their sibling. Furthermore, the scarce research that is available regarding young sibling caregiving experiences in Canada centres on retrospective accounts, which poses its own limitations such as recall bias (Rose & Cohen, 2010; Szafran, et al., 2016). Given the lack of qualitative research focusing specifically on young sibling carers' present caregiving experiences, few programs and services have been established to support their unique needs (e.g. Young Caregivers Association, Powerhouse Project), which suggests that further exploration of this research issue is warranted in order to gain a more detailed picture of young sibling caregiving experiences.

To address this research gap, the current study will seek to qualitatively explore how young Canadians under the age of 25 make sense of caring for their sibling(s). Through publicly accessible interview-based podcasts with young carers who currently provide care to their sibling(s), a more accurate depiction of young sibling carers' experiences may surface. My decision to use podcasts that are freely accessible to the public may help to engage broader audiences and therefore generate greater awareness on this specific population of young carers. Although preliminary, this study is expected to draw greater attention to young Canadian caregivers who provide care to sibling(s), with the hope that social and governmental agencies, healthcare professionals, and society at large will employ novel and updated policies, programs, and services to support young sibling caregivers.

Theoretical Framework

The current study was informed by ecological systems theory (Bronfenbrenner, 1979; 2005), which aligns with previous sibling literature (Lee et al., 2019). This model assumes two key defining principles including, the evolving nature of humans in relationships and the similar but fundamentally different developmental processes that occur overtime (Bronfenbrenner, 2001). Bronfenbrenner (2001) suggests that development reflects the stability and change in biopsychological aspects of human beings as individuals and as groups which continues throughout life across generations and through time. As previously mentioned, the idea of nested circles, which encompasses the microsystem, mesosystem, exosystem, macrosystem, and chronosystem further cement this concept. In the present study, the microsystem assists in understanding young sibling carers' experiences of activities, roles, and interpersonal relationships in their closest environments (i.e., in their role as a caregiver). The mesosystem considers the connections between the young sibling carer and their participation in school and

community. The ways in which a young sibling carer is affected by their parents' work schedules (i.e., a parent's availability to provide care) influences their role as a caregiver and comprises the exosystem. The macrosystem refers to how underlying beliefs and ideologies regarding young sibling caregiving, within and outside of home environments, informs their understanding of their role, and the chronosystem holds space for the developmental changes that occur over time.

When considering the changes that occur, families strive to achieve homeostasis (i.e., resiliency in the face of external disruption) which may be accomplished through adaptation (i.e., making internal changes within the system to preserve the system and its key characteristics) (Bronfenbrenner, 1979). For example, if a child is faced with a sudden health challenge and requires an increased amount of care, the family will experience shifts to their caregiving responsibilities in order to maintain balance within the family system. The ecological systems perspective may underlie some of the reasons why siblings primarily take on the caregiving role (e.g., parents working long hours, cultural norms, etc.) by promoting adaptation to the changes brought upon by the health challenges in an attempt to attain homeostasis within the system. Additionally, because sibling relationships are a sub-system of the larger family system, understanding the meaning-making experiences of caregiving may be related to the idea that siblings are inherently connected and influenced by one another through this sub-system, fostering a sense of responsibility to provide care. Moreover, the changes occurring in other sub-systems may influence the relationship between siblings and their caregiving role. For example, Rivers & Stoneman (2003) found that in families where one sibling was diagnosed with autism, marital relationship stress was correlated with greater negative sibling relationships.

Through the application of ecological systems theory, I gained a more holistic view of young sibling caregivers' experiences because not only was I able to explore aspects of their

microsystem (i.e., their sibling, parents, extended family), but also how aspects of the mesosystem (i.e., friendships, romantic relationships, interactions with school and home settings, etc.), exosystem (i.e., school, work, extra-curricular commitments), macrosystem (i.e., beliefs surrounding young sibling caregiving within the home environment and intersocietal beliefs about young sibling caregiving), and chronosystem (i.e., constancy and change in both the young carer and their environment) play a role in their caregiving experiences.

I will assume an interpretivist epistemological stance that assumes that multiple perspectives are possible (Lincoln & Guba, 1985). My goal is to explore participants' understandings of their caregiving experiences, rather than to generate objective conclusions or generalize the results.

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 (Day et al., 2017). While podcasts are most commonly 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). 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) and purposive sampling (Patton, 1990), a way to determine which data best align with the research

question and target audience (Emmel, 2013), was implemented. The two main features of the podcasts that determined their inclusion in the present study were the age of interviewees and the recipient of their care. As the research involving young carers is currently evolving, there has been much debate on what the appropriate age range is when defining what it means to be a young carer, however Stamatopoulos (2015) argues that the title of young carer is received by those who are under 25 years. In the present study, all 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, making their perspectives relevant to the geographical aspect of the research question. Of the 13 episodes in the series, a total of seven podcasts met the inclusion criteria and were selected to be included in the study. The podcasts ranged from nine to eighteen minutes in length and while the podcasts themselves did not conceal the anonymity of interviewees, I removed all identifying information in the transcription and data analysis processes. 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 (1), developmental disabilities (2), autism spectrum disorder (3), and neurological and mental health disorders (1). It should be noted that those who participated in the podcast did not self-disclose their gender or cultural background, therefore in an effort to avoid misgendering or misculturing, I did not include these aspects of interviewees' identities in the results section.

Data Analysis

Thematic analysis (Braun & Clarke, 2006) was used to analyze the podcast interview transcripts. Thematic analysis is a qualitative research method that identifies and interprets

themes in the data through the generation of codes (i.e., the smallest units of data that are potentially relevant to the research question) (Clarke & Braun, 2017). In the present study, thematic analysis was implemented to identify commonalities in the data to generate themes across interviewees' caregiving experiences through an inductive (i.e., bottom up) approach. Inductive thematic analysis pertains to the idea that the themes are more explicitly linked to the data as opposed to the researcher's theoretical interest (Braun & Clarke, 2006). However, it is recognized that it is nearly impossible for a researcher to rid themselves of all preconceived theoretical and epistemological ideas, therefore the analysis was loosely guided by ecological systems theory (Bronfenbrenner, 1979) to help inform the analysis. Additionally, the level at which themes were identified followed a semantic approach. This meant that I identified themes within the explicit meanings of the data and did not examine underlying ideas, assumptions, and conceptualizations (Braun & Clarke, 2006). A key feature of thematic analysis is its flexibility and accessibility in answering a research question, sample size, data collection, and the various ways in which meanings can be generated from data (Clarke & Braun, 2017). Given the small number of podcasts that met criteria for the present study, thematic analysis proved to be an appropriate method for me to attain greater specificity throughout analysis.

I drew on Braun and Clarke's (2006) six-step model guide to guide the data analysis. The first stage involved familiarizing myself with, and immersing myself in the data through the transcription of podcasts and re-reading of the interview transcripts. At this stage, I also made notes on my initial impressions of the data for potential coding. In the second phase I began manually generating the initial codes which involved organizing the data into meaningful groups. Following this, I 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, I reviewed the themes to ensure that they were related to the initial codes and the entire data set. In this stage a thematic “map” of the analysis was created to help with the refinement of themes. Defining and naming themes followed, where I made my final refinement of details for each theme and generated clear definitions (i.e., the essence of themes) and names for each theme to foster an overall story of the analysis. Finally, I created the final report which involved using examples from the data and relating the analysis back to the research question.

Rigour

I used the following rigour criteria in the study: credibility, dependability, transferrability, and confirmability (Guba & Lincoln, 1989). *Credibility* concerns whether conclusions seem plausible (Guba & Lincoln, 1989). To achieve credibility, I listened to podcasts and read the original transcript multiple times. I also ensured that my results appeared well grounded in direct quotes from the interviews. Since the data collected are in the public domain, readers may assess the credibility of the transcript by accessing the interviews by searching Hidden Voices or The Change Foundation on Apple, Spotify, YouTube, and other streaming websites.

Dependability concerns the study’s integrity or authenticity or whether the analysis process is in line with the accepted standards and can be trusted in terms of its quality or are worth paying attention to (Lincoln & Guba, 1985). Dependability in this study was fostered through keeping the audit trail (Morse, 2015) *Transferability* concerns the extent to which the conclusions can be applied or transferred to another context or setting (Guba & Lincoln, 1989). Prolonged engagement, persistent observation, and thick description were used to promote transferability (Morse, 2015). *Confirmability* concern the fit between the participants’

observable understandings and the researcher's interpretations or conclusions (Guba & Lincoln, 1989).

Reflexivity is one of the most widely used practices in qualitative research (Mitchell et al., 2018) and has been described as the gold standard for determining trustworthiness in research (Teh & Lek, 2018). *Reflexivity* is the process by which a researcher constantly attends to, critically examines, and clearly describes the intersecting connections between participants and themselves (Dodgson, 2019). Reflexivity highlights how a researcher's contextual perspective (i.e., based on values, assumptions, experiences, knowledge, culture, time, place, etc.) shape the conceptualization of research and knowledge. In doing so, the researcher can gain a more thorough understanding of their work (Dodgson, 2019), which increases the trustworthiness of their research. I practiced reflexivity by attending to my own perspectives and how these potentially affected my interpretation of the data. I achieved this by documenting notes on the side of the transcripts. Being a young sibling caregiver myself, there were certainly aspects of the data that mirrored my personal experience and captured my attention. I feel that my experience added to the trustworthiness and reflexivity of the research because I was able to attend to aspects of narratives that resonated with me on a more personal level, that may have been missed if I had not experienced what it was like to be a young sibling caregiver. At the same time, I tried to keep an open mind to experiences of interviewees that did not parallel my experience.

Results

The thematic analysis resulted in the identification of eight themes, each of which are discussed below. These included: *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 a number of 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". This reflection describes how the young carer developed an increased capacity to be flexible and more understanding of their siblings' challenges, even if that means sacrificing their own preferences to accommodate their siblings' needs. 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. One interviewee (age 8) 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 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 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 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 prioritising 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 on a daily basis trying to negotiate competing roles and responsibilities. One interviewee (age 16) described 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 Judgment

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:

Well 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.

Through this quotation, it is evident that this young sibling carer feels 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 aspects of what it means to be a young sibling carer. Others described that while 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.

In order 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) 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.

It is clear that 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) 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

I used thematic analysis to analyze seven interview-style podcasts to explore how young Canadians under the age of 25 living in Ontario make sense of their sibling caregiving experiences. A number of 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. To my knowledge, this is the first study that has incorporated online interview data specific to young sibling carers' accounts of their present caregiving experiences. The process of analyzing podcasts evokes 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). Moreover, the conversational nature of interview podcasts may alleviate participant distress commonly noted in research settings when discussing

emotionally challenging topics (Flagel et al., 2007; Gibbs et al., 2018). Prior studies explore young sibling carers as indistinct from young carers in general by identifying which areas of their lives are affected, such as psychosocial distress and burden, disruption of educational and career pursuits, and feeling a lack of control over their lives, paired with feelings of accomplishment, independence, and maturity are common experiences felt among both groups (Stamatopoulos, 2018). Moreover, the present literature on sibling caregiving in Canada highlights participants' retrospective accounts of caregiving and may be subject to recall bias (Rose & Cohen, 2010; Szafran, et al., 2016). Since this population of young carers experiences 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 work is needed that is detailed and that specifies *how* sibling carers make sense of their experiences. Doing so may help distinguish the unique differences that this particular 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 more accurate understanding of what it means to be a young sibling caregiver.

In the present study, 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. Therefore, it is evident that there is struggle in these experiences.

However, interviewees consistently seemed to acknowledge the value and benefits they have gained from their young sibling caregiving journey. The amalgamation of conflicting feelings is a common experience for caregivers at any age, and Cheung and Hocking (2004) describe this as a paradox of emotions that arise as changes are introduced into the lives of carers. However, young carers having a sense of appreciation for these aspects of growth, especially when comparing themselves to their peers, may foster feelings of competence, empathy, and compassion that could be extended beyond family relationships to other relationships (Stamatopoulos, 2018). Moreover, holding onto hope and their ability to persevere despite facing multiple challenges, may serve as positive tools that heighten young sibling carers' level of resilience throughout their lifetime.

Aligning with pre-existing literature (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 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 as a result 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). Health, psychological, financial, and other costs of being a caregiver are also well documented in the broader caregiving literature (Karantzas, 2012; Montgomery et al., 2007; Schulz & Czaja, 2018; Schulz & Eden, 2016).

The challenges experienced by interviewees in this study subtly eluded to dominant Western ideals of family roles and relationships as well as 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 inaccurate perceptions 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 were 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 (Dearden & Becker, 2000; Levine et al., 2005; Stamatopoulos, 2018; Szafran et al., 2016; Watt et al., 2017). 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 reality a secret from others. The notion of secrecy has come up in pre-existing literature as a means to maintain family solidarity (Szafran et al., 2016), 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 sense of responsibility 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). However, 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. The interviewees in this study described their experiences of juggling academics, social lives, and their role as a young sibling carer. Balancing multiple roles is a common experience among this population, and Szafran et al. (2016) reports that this has much to do with the levels of stress, burn out, and exhaustion young carers experience at a young age.

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 engaging with ADLs and IADLs (Bauman et al., 2006; Kavanaugh, 2014; Keigher, et al., 2005; Lackey & Gates, 2001; Shifren, 2008; Shifren & Kachorek, 2003; 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, carers sacrificing their personal and social experiences to mitigate sibling distress, and worrying about their sibling. 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 (Aldridge & Becker, 1999; 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. 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 in their study, and how this

acted as a long-lasting repercussion in adulthood (i.e., inability to trust others and make meaningful, positive relationships).

Ecological systems theory (Bronfenbrenner, 2005) and attachment theory (Bowlby, 1969) may explain the high level of emotional attunement that young carers and their siblings (i.e., care recipients) experienced in the present study. Bronfenbrenner (2005) argues that dyads are the critical units of analysis at the level of the microsystem and supportive sibling relationships and their subsequent activities and roles based on stage of development influence one another (Whiteman et al., 2011). Moreover, Bowlby (1969) posits that as children develop, they familiarize themselves with their social environments and turn to their siblings for emotional security to understand relationships, expectations, and behaviours, which may strengthen their attachment to each other (Whiteman et al., 2011). The importance placed on maintaining sibling bonds through engaging in activities, or the joy and meaning that emotional attunement brought to interviewees in the present study, speaks to the ability of young sibling carers to make positive meaning out of their experiences. Previous studies have revealed that one of the positive impacts of young sibling caregiving include stronger intimate bonds with loved ones (i.e., primarily the sibling care recipient) (Pakenham, 2005; Remtulla et al., 2012; Szafran et al., 2016).

The qualitative research on the experiences of young sibling caregiving highlights the notion that individuals undertake this role when parental support is limited (Stamatopoulos, 2015, Szafran, et al., 2016). Interestingly, in the present study, there was no indication by interviewees that parents experienced their own illnesses, faced substance related challenges, or were simply absent from the home. While this may not be something that interviewees would openly discuss due to stigma, maintaining solidarity with the family, or to prevent feelings of betrayal (Szafran, et al., 2016), it may highlight the bi-directional influences and motivations for

sibling caregiving described in ecological systems theory (Bronfenbrenner, 2001). Since bi-directional influences have the greatest impact on an individual at the level of the microsystem (Bronfenbrenner, 2001), when change occurs (i.e., health challenges faced by a sibling), it makes sense that well-siblings would evolve into a caregiving role to maintain homeostasis within the family system.

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 the duties they are undertaking are in fact categorized as duties upheld by a caregiver (Aldridge & Becker, 2003; Hounsell, 2013; Lackey & Gates, 2001; McGibbon, et al., 2018). Research reveals that some of the motivations for young caregiving roles include, but are not limited to, a lack of services for the care recipient and their families (McDonald et al., 2009), resistance to services due to stigma and financial barriers (Aldridge, 2018), cultural and familial desires to provide care from within the family (Leu et al., 2018), and children’s desires to undertake care (Hanna & Chisnell, 2019). 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. Moreover, it has been reported that even 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 (Aldridge, 2018; McDonald, et al., 2009; Sprung & Laing, 2017). Indeed, this may relate to the idea of family members striving to achieve

homeostasis from a ecological systems theory (Bronfenbrenner, 2005) perspective. In these instances, it could be hypothesized that young sibling carers are met with the opportunity to bring about a sense of balance, and therefore naturally adapt to their changing family dynamics, placing them in the young sibling caregiver role.

Implications

Results from this study have several implications for various stakeholders such as 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) may hinder health care providers from recognizing young carers' own caring needs and challenges. Based on the results of this study and other research, it is clear that 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. For example, a referral to a family therapist or other counselling services has been known to be effective in achieving positive outcomes and increasing quality of life through enhancing knowledge, skills, and support, as well as through increasing carers' confidence levels and their ability to manage daily care challenges (Schulz & Czaja, 2018). Additionally, through counselling services, young sibling carers can identify their specific individual needs and tend to the multitude of conflicting emotions that present along this experience. Research on young carers in the United Kingdom (UK) revealed that taking a more

holistic approach (i.e., whole family) has positively impacted and addressed the needs of young carers and care recipients and mitigates the reinforcement of young carers remaining in this role (Stamatopoulos, 2016). A holistic approach to care also addresses the needs of the whole family system, as opposed to focusing solely on the caregiver, fostering family resiliency (Charles, et al., 2012; Ronicle & Kendall, 2011). Furthermore, such an approach removes the pathologizing notion that one single person in the family dynamic is the “problem” and operates from a strengths-based perspective (Walter & Petr, 2000). Therefore, if therapists and other health care providers encounter young sibling carers in their practice, they should consider involving the whole family in sessions to systemically explore and effectively manage their care burden through open dialogue of all members.

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 counselling services accessible to young sibling carers, is through implementing this in school settings. In her qualitative review of young carer supports in Canada, Stamatopoulos (2016) explored three programs available to young carers (i.e., that operated within schools) that aimed at assisting and alleviating some of the negative implications that emerge from being in this role. Moreover, teachers, school nurses, and office staff have a role in identifying and protecting young carers as they could provide mentorship and a safe space for young sibling carers to express their challenges, strengthen their skills and agency, and promote advocacy (Charles et al., 2008). 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 (Abraham & Aldridge, 2010). More broadly, schools could make an effort 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 find benefit to the results of this study. It 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 Change Foundation. Having this sense of support may serve as a protective factor along the young sibling caregiving journey. Through this research, young sibling carers may also recognize that their experiences differ from each other and that there is no uniform way of defining what it means to be a young sibling carer. Moreover, they may be able to differentiate their values of caring for a sibling and what it means to be a young sibling carer. This may lead to inviting the term young carer into their identity, which may increase their comfortability in accessing resources, supports, and services that are tailored to their needs. 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 access the supports that are currently available in Canada.

It is clear that insufficient funding is a barrier to providing a wide range of services that accommodate young carers, since the Canadian state prioritizes macro-level policy changes that are geared towards individualized approaches to healthcare and social service delivery (Stamatopoulos, 2016). 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 this population properly supported. These institutions may consider increasing funding for counselling, schools, and participant-led (i.e., young sibling carers), action-focused research studies, which advocate for young sibling carers, both those who identify in this role and those who remain hidden.

Limitations

Although this study garnered insight on interviewees' meaning making experiences in their present role as young sibling caregivers, there are some limitations that warrant acknowledgment. Firstly, since the data were collected from previously recorded online podcasts, I did not have the opportunity to engage with interviewees directly nor follow up with them. Similarly, it was not possible for me to directly ask interviewees about their caregiving experiences in greater detail, nor check if my 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 bias and/or cultural misrepresentations that overemphasize negative aspects of caregiving. Social desirability bias is defined as the inclination to express oneself and one's social context in a way that is socially acceptable, but not fully representative of one's reality (Bergen & Labonte, 2020). Given the nature of these interviews (i.e., conducted by a stranger), who can access to them (i.e., available on most public podcast streaming platforms), and interviewees' lack of anonymity, it is possible that these factors may have influenced the ways in which interviewees' discussed their role as young sibling carers, highlighting more positive aspects over negative ones. Moreover, due to society's focus on the negative implications of caregiving, interviewees may have felt compelled to challenge this view as it as not wholly

reflective of the young sibling caregiving experience, and therefore accentuated the positive impacts that caregiving has had on their lives and minimizing the negatives. Thirdly, while the results may be transferrable or 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. Fourth, while my personal experiences of being a young sibling carer aided in my understanding, conceptualization, and construction of interviewees' experiences, it must be noted that there lies the possibility that my assumptions and subsequent interpretations of interviewees' experiences may be based on my own experiences.

Finally, the lack of clarity regarding interviewees' gender and cultural background, serves as a limitation for this study because broader sibling caregiving literature reflects that gender and culture play a role in sibling caregiving experiences and the implications emanating from fulfilling this role (Namkung et al., 2017). For example, research suggests that siblings from collectivist cultures tend to have closer relationships than those in the majority culture, which may account for the reasons why white sibling carers experience lower positive well-being than their minority counterparts (Namkung et al., 2017). Gold's (1990) work on adult sibling relationships revealed that racialized siblings are more likely to preserve positive relationships with one another, have more positive attitudes towards their siblings, and express greater interest in providing support to siblings when compared to white siblings. Moreover, Namkung et al. (2017) found that white sibling caregivers reported a higher number of depressive symptoms, lower levels of life satisfaction, and lower perceived control as compared to non-white and minority sibling caregivers. These findings may highlight the fact that people in minority groups may be more likely to have stronger bonds with siblings and as such, may view

caregiving as a normative experience with less negative implications (Namkung et al., 2017).

Consequently, more research is needed to determine whether these findings are replicated among young sibling carers in Ontario.

Future Directions

Future 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 and cultural backgrounds 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.

Conclusion

The research herein explored how young Canadian sibling caregivers living in Ontario make sense of their caregiving experiences. It is evident that meaning-making experiences encompass a wide variety of mixed emotions and challenges, as well as a sense of resilience and perseverance that are informed by the many identities these interviewees hold outside of being a young carer. It is critical that macro-level organizations (e.g., governmental agencies, healthcare

professionals, policy-makers, etc.) play a role in raising awareness for this population and that they continue to enforce accessible resources and supports that mitigate caregiver burden (i.e., through prevention) and work towards increasing and improving the factors that underlie the positive implications of young sibling caregiving.

REFERENCES

- Abraham, K., & Aldridge, J. (2010). *Who Cares About Me?* In Manchester Carer Forum. Manchester, UK.
- Abrams, M. S. (2009). The well sibling: Challenges and possibilities. *American Journal of Psychotherapy*, 63(4), 305–317. <https://doi.org/10.1176/appi.psychotherapy.2009.63.4.305>
- Albert, S. M. (1991). Cognition of caregiving tasks: Multidimensional scaling of the caregiver task domain. *Gerontologist*, 31(6), 726–734. <https://doi.org/10.1093/geront/31.6.726>
- Aldridge, J. (2018). Where are we now? Twenty- five years of research, policy and practice on young carers. *Critical Social Policy*, 38(1), 155–165. doi:10.1177/0261018317724525
- Aldridge, J., & Becker, S. (1999). Children as carers: The impact of parental illness and disability on children’s caring roles. *Journal of Family Therapy*, 21, 303-320.
- Aldridge, J., & Becker, S. (2003). Children caring for parents with mental illness: perspectives of young carers, parents and professionals. Bristol, England: The Policy Press.
- Amato, P. R. (1989). Family Processes and the Competence of Adolescents and Primary School Children. *Journal of Youth and Adolescence*, 18, 39–53.
- Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist*, 37(3), 342–354. <https://doi.org/10.1093/geront/37.3.342>
- Armstrong, P., & Armstrong, H. (2005). Public and private: Implications for care work. *Sociological Review*, 53(2), 167-187.
- Barg, F. K., Keddem, S., Cohen, W. S., & Henderson, R. (2014). An Anthropology of

- Caregiving. In R. C. Talley & S. S. Travis (Eds.), *Multidisciplinary Coordinated Caregiving, Caregiving: Research, Practice, Policy* (pp. 177–194). Springer Science+Business Media. <https://doi.org/10.1007/978-1-4614-8973-3>
- Barry, M. (2011). “I realised that I wasn’t alone”: The views and experiences of young carers from a social capital perspective. *Journal of Youth Studies, 14*(5), 523–539. <https://doi.org/10.1080/13676261.2010.551112>
- Bastawrous, M. (2013). Caregiver burden-A critical discussion. *International Journal of Nursing Studies, 50*, 431–441. <https://doi.org/10.1016/j.ijnurstu.2012.10.005>
- Bauman, L., Foster, G., Johnson-Silver, L., Berman, R., Gamble, I., & Muchaneta, L. (2006). Children caring for their ill parents with HIV/AIDS. *Vulnerable Children and Youth Studies, 1*(1), 56–70.
- Becker, S. (2007). Global perspectives on children’s unpaid caregiving in the family: Research and policy on ‘young carers’ in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy, 7*(23), 23-50. doi: 10.1177/1468018107073892
- Becker, S., & Dearden, C. (2005). CARERS. *Research Matters, 18*, 11–18.
- Beeson, R., Horton-Deutsch, S., Farran, C., & Neundorfer, M. (2000). Loneliness and depression in caregivers of persons with Alzheimer’s disease or related disorders. *Issues in Mental Health Nursing, 21*(8), 779–806. <https://doi.org/10.1080/016128400750044279>
- Bergen, N. & Labonte, R. (2020). "Everything is perfect, and we have no problems": Detecting and Limiting Social Desirability Bias in Qualitative Research. *Qualitative Health Research, 30*(5), 783-792. doi: 10.1177/1049732319889354

- Bolas, H., Wersch, A. V., & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology and Health*, 22(7), 829-850. doi:10.1080/14768320601020154
- Boll, T., Ferring, D., Filipp, S.H. (2003). Perceived parental differential treatment in middle adulthood: Curvilinear relations with individuals' experienced relationship quality to sibling and parents. *Journal of Family Psychology*, 17(4), 472-487.
- Bowlby, J. (1969). Attachment and Loss, Vol. 1: Attachment. Attachment and Loss. In *Attachment*.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-10.
- Brewer, L. (2001). Gender socialization and the cultural construction of elder caregivers. *Journal of Aging Studies*, 15, 217–235. [https://doi.org/10.1016/S0890-4065\(01\)00020-2](https://doi.org/10.1016/S0890-4065(01)00020-2)
- Brody, E. M. (1990). *Women in the middle: Their parent-child years*. New York: Springer.
- Brody, G. H. (1998). Sibling Relationship Quality: Its Causes and Consequences. *Annual Review of Psychology*, 49, 1–24.
- Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Harvard University Press.
- Bronfenbrenner, U. (1986). Ecology of the Family as a Context for Human Development: Research Perspectives. *Developmental Psychology*, 22, 723–742.
<https://doi.org/10.1037/0012-1649.22.6.723>
- Bronfenbrenner, U. (2001). *The Bioecological theory of human development*. In U.

- Bronfenbrenner (Ed.), *Making Human Beings Human: Bioecological Perspectives on Human Development* (pp. 3–15). Thousand Oaks, California: Sage Publications.
- Bronfenbrenner, U. (2005). *Ecological systems theory (1992)*. In U. Bronfenbrenner (Ed.), *Making human beings human: Bioecological perspectives on human development* (p. 106–173). Sage Publications Ltd.
- Burke, P., & Montgomery, S. (2001). Brothers and sisters: Supporting the siblings of children with disabilities. *Practice: Social Work in Action, 13*(1), 27-38.
- Carpenter, E., & Miller, B. (2002). Psychosocial Challenges and Rewards Experienced by Caregiving Men: A Review of the Literature and an Empirical Case Example. In B. Kramer & E. Thompson (Eds.), *Men as Caregivers*. Prometheus Books.
- Carriere, J. & Richardson, C. (2009). From longing to belonging: Attachment theory, connectedness, and Indigenous children in Canada. In S. McKay, D. Fuchs, & I. Brown (Eds.), *Passion for Action in the Child and Family Services: Voices from the Prairies* (pp/ 46-67. Canadian Plains Research Centre.
- Chadi, N., & Stamatopoulos, V. (2017). Caring for young carers in Canada. *Canadian Medical Association Journal, 189*(28), E925–E926. <https://doi.org/10.1503/cmaj.170145>
- Chappell, N. L., Dujela, C., & Smith, A. (2014). Spouse and adult child differences in caregiving burden. *Canadian Journal on Aging, 33*(4), 462–472.
<https://doi.org/10.1017/S0714980814000336>
- Charles, G. (2011). Bringing Young Carers out of the Shadows. *Reclaiming Children and Youth, 20*(3), 26–30.
- Charles, G., Marshall, S., & Stainton, T. (2010). Demographics, Profiles and Initial Results from the British Columbia Young Carers Study. *Relational Child and Youth Care Practice,*

23(4), 64–67.

Charles, G., Stainton, T., & Marshall, S. (2008). Young Carers in Canada: An Invisible Population. *Relational Child and Youth Care Practice*, 21(4), 5–12.

Charles, G., Stainton, T., & Marshall, S. (2012). Young carers in Canada: The hidden costs and benefits of young caregiving. Ottawa: Vanier Institute of the Family. Retrieved from <http://www.vanierinstitute.ca/modules/news/newsitem.php>

Cheung, J., & Hocking, P. (2004). The experience of spousal carers of people with multiple sclerosis. *Qualitative Health Research*, 14(2), 153–166.

Chumbler, N. R., Grimm, J. W., Cody, M., & Beck, C. (2003). Gender, kinship and caregiver burden: The case of community-dwelling memory impaired seniors. *International Journal of Geriatric Psychiatry*, 18(8), 722–732. <https://doi.org/10.1002/gps.912>

Cicirelli, V. G. (1995). *Sibling Relationships Across the Life Span*. Plenum Press.

Clandinin, D. J., Pushor, D., & Orr, A. M. (2007). Navigating Sites for Narrative Inquiry. *Journal of Teacher Education*, 58(1), 21–35. <https://doi.org/10.1177/0022487106296218>

Clarke, V. & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, 12(3), 297-298.

Collins, P.H. (1987). The meaning of motherhood in Black culture and Black mother/daughter relationships. *SAGE: A Scholarly Journal on Black Women*, 4(2), 3-10.

Connelly, F. M., & Clandinin, D. J. (2006). Narrative Inquiry. In J. L. Green, G. Camilli, & P. Elmore (Eds.), *Handbook of Complementary Methods in Education Research* (3rd ed., pp. 477–487). Lawrence Erlbaum.

Connidis, I. A., & McMullin, J. A. (2002). Sociological ambivalence and family ties: A critical

- perspective. *Journal of Marriage and Family*, 64, 558–567. <https://doi.org/10.1111/j.1741-3737.2002.00558.x>
- Coon, D. W., Rubert, M. P., Solano, N., Mausbach, B., Kraemer, H., Arguëlles, T., Haley, W. E., Thompson, L. W., & Gallagher-Thompson, D. (2004). Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: Findings from the REACH study. *Aging and Mental Health*, 8(4), 330–345. <https://doi.org/10.1080/13607860410001709683>
- Cresswell, J. W. (2007). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches* (2nd ed.). Sage Publications.
- Day, L., Cunsolo, A., Castleden, H., Martin, D., Hart, C., Anaviapik-Soucie, T., Russell, G., Paul, C., Dewey, C., & Harper, S. L. (2017). The expanding digital media landscape of qualitative and decolonizing research: Examining collaborative podcasting as a research method. *MediaTropes*, 7(1), 203-228.
- Dearden, C., & Becker, S. (2000). Growing up caring. Leicester, England: Youth Work Press and The Joseph Rowntree Foundation.
- Delgado, J. (1997). *Salud: A Latina's Guide to Total Health- Body, Mind, and Spirit*. Harper Collins.
- Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of race on cultural justifications for caregiving. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 60(5), 257–262. <https://doi.org/10.1093/geronb/60.5.S257>
- Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer*

Disease and Associated Disorders, 16, S56–S63. <https://doi.org/10.1097/00002093-200200002-00005>

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *The Gerontologist*, 42, 237–272.

Dodgson, J. E. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, 35(2), 220–222.

Dunn, J. (1992). Sisters and brothers: Current issues in developmental research. In F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues*.

Dunn, J. (1993). *Young Children's Close Relationships*. Sage.

Emmel, N. (2013). Purposeful sampling. Sampling and choosing cases in qualitative research: A realist approach, 33-45.

England, P., & Folbre, N. (1999). The cost of caring. *The Annals of the American Academy of Political and Social Science*, 561(1), 39-51. doi: 10.1177/000271629956100103

Flagel, D.C., Best, L.A., Hunter, A.C. (2007). Perceptions of stress among students participating in psychology research: A Canadian survey. *Journal of Empirical Research on Human Research Ethics: An International Journal*, 2(3), 61-67.

Fortuna, K., Roisman, G. I., Haydon, K. C., Groh, A. M., & Holland, A. S. (2011). Attachment States of Mind and the Quality of Young Adults' Sibling Relationships. *Developmental Psychology*, 47(5), 1366–1373. <https://doi.org/10.1037/a0024393>

Franklin, D. (1997). *Ensuring Inequality: The Structural Transformation of the African-American Family*. Oxford University Press.

- Gibbs, L., Molyneaux, R., Whiteley, S., Block, K., Harms, L., Bryant, R.A., Forbes, D., Gallagher, H.C., MacDougall, C., Ireton, G. (2018). Distress and satisfaction with research participation: Impact on retention in longitudinal disaster research. *International Journal of Disaster Risk Reduction*, 27(1), 68-74.
- Goetting, A. (1986). The Developmental Tasks of Siblingship over the Life Cycle. *Journal of Marriage and the Family*, 48(4), 703. <https://doi.org/10.2307/352563>
- Gold, D. T. (1990). Late-life sibling relationships: Does race affect typological distribution? *The Gerontologist*, 30(6), 741–748. <https://doi.org/10.1093/geront/30.6.741>
- Goode, W. (1960). A theory of role strain. *American Sociological Review*, 25, 483-496.
- Grant, G., Repper, J., & Nolan, M. (2008). Young people supporting parents with mental health problems: experiences of assessment and support. *Health & Social Care in the Community*, 16(3), 271-281. doi:10.1111/j.1365-2524.2008.00766.x
- Haley, W. E., Gitlin, L. N., Wisniewski, S. R., Mahoney, D. F., Coon, D. W., Winter, L., Corcoran, M., Schinfeld, S., & Ory, M. (2004). Well-being, appraisal, and coping in African-American and Caucasian dementia caregivers: Findings from the REACH study. *Aging and Mental Health*, 8(4), 316–329. <https://doi.org/10.1080/13607860410001728998>
- Haley, W. E., West, C. A. C., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. S., Harrell, L. E., & Roth, D. L. (1995). Psychological, Social, and Health Impact of Caregiving: A Comparison of Black and White Dementia Family Caregivers and Noncaregivers. *Psychology and Aging*, 10(4), 540–552. <https://doi.org/10.1037/0882-7974.10.4.540>

- Hanna, S., & Chisnell, C. (2019). An invisible population – young carers in Aotearoa New Zealand. *Aotearoa New Zealand Social Work*, 31(2), 7–17.
doi:10.11157/anzswjvol31iss2id636
- Hooker, K., Manoogian-O'Dell, M., Monahan, D. J., Frazier, L. D., & Shifren, K. (2000). Does type of disease matter? Gender differences among alzheimer's and parkinson's disease spouse caregivers. *Gerontologist*, 40, 568–573. <https://doi.org/10.1093/geront/40.5.568>
- Horwitz, A. V., & Reinhard, S. C. (1995). Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses. *Journal of Health and Social Behavior*, 36(2), 138–150. <https://doi.org/10.2307/2137221>
- Hounsell, D. (2013). Hidden from view: the experiences of young carers in England. London, England: The Children's Society. Retrieved from
https://www.childrenssociety.org.uk/sites/default/files/hidden_from_view_final.pdf
- Hudson, L., & Ozanne, J. (1988). Alternative Ways of Seeking Knowledge in Consumer Research. *Journal of Consumer Research*, 14(4), 508–521.
- Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. *Gerontologist*, 41(3), 334–347.
<https://doi.org/10.1093/geront/41.3.334>
- Jessup, N. M., Bakas, T., McLennon, S. M., & Weaver, M. T. (2015). Are there gender, racial or relationship differences in caregiver task difficulty, depressive symptoms and life changes among stroke family caregivers? *Brain Injury*, 29(1), 17–24.
<https://doi.org/10.3109/02699052.2014.947631>

- Joseph, S., Sempik, J., Leu, A., Becker, S. (2020). Young carers research, practice and policy: An overview and critical perspective on possible future directions. *Adolescent Research Review*, 5(1), 77-89.
- Karantzas, G.C. (2012). Family caregiving: Perspectives of adult children and older parents. In P. Noller & G.C. Karantzas (Eds.), *The Wiley-Blackwell Handbook of Couples and Family Relationships* (pp. 82-96). Blackwell Publishing Ltd.
- Kavanaugh, M. (2014). Children and adolescents providing care to a parent with Huntington's disease: Disease symptoms, caregiving tasks and young carer well-being. *Child & Youth Care Forum*, 43(6), 675–690.
- Kinkaid, E., Emard, K., Senanayake, N. (2020). The podcast-as-method?: Critical reflections on using podcasts to produce geographic knowledge. *Geographical review*, 110(1-2), 78-91.
- Keigher, S., Zabler, B., Robinson, N., Fernandez, A., & Stevens, P. (2005). Young caregivers of mothers with HIV: Need for supports. *Children and Youth Services Review*, 27(1), 881–904.
- Keith, C. (1995). Family Caregiving Systems: Models, Resources, and Values. *Journal of Marriage and the Family*, 57(1), 179–190. <https://doi.org/10.2307/353826>
- Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68(4), 846–855. <https://doi.org/10.1111/j.1365-2648.2011.05787.x>
- King, R. B., Hartke, R. J., & Houle, T. T. (2010). Patterns of relationships between background characteristics, coping, and stroke caregiver outcomes. *Topics in Stroke Rehabilitation*,

17(4), 308–317. <https://doi.org/10.1310/tsr1704-308>

- Knight, B. G., Silverstein, M., McCallum, T. J., & Lauren S, F. L. (2000). A sociocultural stress and coping model for mental health outcomes among African American caregivers in Southern California. *Journals of Gerontology: Psychological Sciences*, 55B(3), 142–150. <https://doi.org/10.1093/geronb/55.3.P142>
- Kramer, L., & Hamilton, T. N. (2019). Sibling Caregiving. *Handbook of Parenting*, 3(1), 372–408. <https://doi.org/10.4324/9780429433214-11>
- Lackey, N., & Gates, M. (2001). Adults' recollections of their experiences as young caregivers of family members with chronic illnesses. *Journal of Advanced Nursing*, 34(3), 320–328.
- Lakman, Y. & Chalmers, H. (2019). Psychosocial comparison of carers and non-carers. *Child & Youth Services*, 40(2), 200-219.
- Lakman, Y., Chalmers, H., & Sexton, C. (2017). Young carers' educational experiences and support: A roadmap for the development of school policies to foster their academic success. *Alberta Journal of Educational Research*, 63(1), 63–74.
- Lawrence, J. A., Goodnow, J. J., Woods, K., & Karantzas, G. (2002). Distributions of caregiving tasks among family members: The place of gender and availability. *Journal of Family Psychology*, 16(4), 493–509.
- Lawton, M. P., Rajagopal, D., Brody, E., & Kleban, M. H. (1992). The dynamics of caregiving for demented elders among black and white families. *Journals of Gerontology*, 47, S156–S164. <https://doi.org/10.1093/geronj/47.4.S156>
- Lee, C., Burke, M., Arnold, C. K., & Owen, A. (2019). Correlates of Current Caregiving Among Siblings of Adults with Intellectual and Developmental Disabilities. *Journal of Applied*

- Research in Intellectual Disabilities*, 32(6), 1490–1500.
- Lee, Y. & Tang, F. (2015). More caregiving, less working: Caregiving roles and gender difference. *Journal of Applied Gerontology*, 34(4), 465-483. doi: 10.1177/0733464813508649
- Lefley, H. P. (1990). Culture and chronic mental illness. *Hospital and Community Psychiatry*, 41(3), 277–286. <https://doi.org/10.1176/ps.41.3.277>
- Leu, A., Frech, M., & Jung, C. (2018). Young carers and young adult carers in Switzerland: caring roles, ways into care and the meaning of communication. *Health and Social Care in the Community*, 26(6), 925–934. doi:10.1111/hsc.12622
- Levine, C., Hunt, G. G., Halper, D., Hart, A. Y., Lautz, J., & Gould, D. A. (2005). Young adult caregivers: a first look at an unstudied population. *American Journal of Public Health*, 95(11), 2071–2075. doi:10.2105/AJPH.2005.067702
- Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Sage.
- Liu, D., Hinton, L., Tran, C., Hinton, D., & Barker, J. C. (2008). Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross-Cultural Gerontology*, 23(3), 283–299. <https://doi.org/10.1007/s10823-008-9075-5>
- Magaña, S., Seltzer, M. M., & Krauss, M. W. (2004). Cultural context of caregiving: Differences in depression between Puerto Rican and non-Latina white mothers of adults with mental retardation. *Mental Retardation*, 42(1), 1–11. [https://doi.org/10.1352/0047-6765\(2004\)42<1:CCOCDI>2.0.CO;2](https://doi.org/10.1352/0047-6765(2004)42<1:CCOCDI>2.0.CO;2)
- Marin, G., & Marin, B. (1991). *Research with Hispanic Populations*. Sage.

- Maynard, A. E. (2004). Sibling Interactions. In U. P. Gielen & J. Roopnarine (Eds.), *Childhood and Adolescence: Cross-Cultural Perspectives and Applications. Advances in Applied Developmental Psychology* (pp. 229–252). Praeger.
- McDonald, J., Cumming, J., & Dew, K. (2009). An exploratory study of young carers and their families in New Zealand. *Kōtuitui: New Zealand Journal of Social Sciences Online*, 4(2), 115–129. doi:10.1080/1177083X.2009.9522448
- McGibbon, M., Spratt, T., & Davidson, G. (2018). Young carers in Northern Ireland: perceptions of and responses to illness and disability within the family. *British Journal of Social Work*, 49(5), 1162–1179. doi:10.1093/bjsw/bcy102
- McHale, S. M., Updegraff, K. A., Shanahan, L., Crouter, A. C., & Killoren, S. E. (2005). Siblings' differential treatment in Mexican American families. *Journal of Marriage and Family*, 67, 1257–1274. <https://doi.org/10.1111/j.1741-3737.2005.00215.x>
- McShane, L.A. & Hastings, P.D. (2004). Culturally sensitive approaches to research on child development and family practices in first peoples communities. *First Peoples Child and Family Review*, 1(1), 38-44.
- Mitchell, J., Boettcher-Sheard, N., Duque, C., & Lashewicz, B. (2018). Who do We Think We are? Disrupting Notions of Quality in Qualitative Research. *Qualitative Health Research*, 28(4), 673–680.
- Montgomery, R. J. V., & Kosloski, K. (2000a). Family caregiving: Change, continuity, and diversity. In R. Rubinstein & M. Lawton (Eds.), *Alzheimer's disease and related dementias: Strategies in care and research* (pp. 143–171). New York: Springer.
- Montgomery, R. J., & Kosloski, K. D. (2000b). *Change, continuity and diversity among*

caregivers (pp. 1-18). Administration on Aging.

Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (2007). Family Caregiving. In J. A.

Blackburn & C. N. Dulmus (Eds.), *Handbook of gerontology: evidence-based approaches to theory, practice, and policy* (pp. 426–454). John Wiley & Sons, Inc.

Morse, J. M. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry.

Qualitative Health Research, 25(9), 1212–1222.

Namkung, E. H., Greenberg, J. S., & Mailick, M. R. (2017). Well-being of Sibling Caregivers:

Effects of Kinship Relationship and Race. *Gerontologist*, 57(4), 626–636.

<https://doi.org/10.1093/geront/gnw008>

Nanda, S., & Warms, R. L. (2010). *Cultural Anthropology* (10th ed.). Cengage Learning.

National Family Caregivers Association (1998). Caregiving across the life-cycle. Maryland:

National Family Caregivers Association. Retrieved April 12, 2020, from

www.thefamilycaregiver.org/who_are_family_caregivers/caregiving_survey.cfm.

Neal, M. B., Ingersoll-Dayton, B., & Starrels, M. E. (1997). Gender and relationship differences

in caregiving patterns and consequences among employed caregivers. *Gerontologist*, 37(6),

804–816. <https://doi.org/10.1093/geront/37.6.804>

Neckoway, R., Brownlee, K., Castellan, B. (2007). Is attachment theory consistent with

Aboriginal parenting realities? *First Peoples Child & Family Review*, 3(2), 65-74.

Noonan, A. E., & Tennstedt, S. L. (1997). Meaning in caregiving and its contribution to

caregiver well-being. *Gerontologist*, 37(785), 794. <https://doi.org/10.1093/geront/37.6.785>

Nuttall, A.K., Coberly, B., Diesel, S.J. (2018). Childhood caregiving roles, perceptions of

benefits, and future caregiving intentions among typically developing adult siblings of

individuals with Autism Spectrum Disorder. *Journal of Autism and Developmental*

Disorders, 48(4), 1199-1209.

Pakenham, K. I. (2005). The positive impact of multiple sclerosis (MS) on carers: associations between carer benefit finding and positive and negative adjustment domains. *Disability and Rehabilitation*, 27(17), 985–997. doi:10.1080/09638280500052583

Park, M., & Lee, K.-J. (2017). Korean sibling caregivers of individuals diagnosed with schizophrenia. *Asian/Pacific Island Nursing Journal*, 2(3), 97–102.
<https://doi.org/10.9741/23736658.1066>

Patton, M. Q. (1990) *Qualitative Evaluation and Research Methods* (Newbury Park: Sage Publications).

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30(5), 583–594.
<https://doi.org/10.1093/geront/30.5.583>

Penning, M. J., & Wu, Z. (2015). Caregiver stress and mental health: Impact of caregiving relationship and gender. *Gerontologist*, 56(6), 1102–1113.
<https://doi.org/10.1093/geront/gnv038>

Picot, S. J., Debanne, S. M., Namazi, K. H., & Wykle, M. L. (1997). Religiosity and perceived rewards of Black and White caregivers. *Gerontologist*, 37(1), 89–101.
<https://doi.org/10.1093/geront/37.1.89>

Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist*, 45(1), 90–106.
<https://doi.org/10.1093/geront/45.1.90>

Pinquart, M., & Sörensen, S. (2006). Gender differences in caregiver stressors, social resources,

- and health: An updated meta-analysis. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 61(1), 33–45. <https://doi.org/10.1093/geronb/61.1.P33>
- Powers, B. A., & Knapp, T. R. (2011). *Dictionary of Nursing Theory and Research* (A. Graubard (ed.); 4th ed.). Springer Publishing Company.
- Pratto, F., & Walker, A. (2004). The Bases of Gendered Power. In A. H. Eagly, A. E. Beall, & R. J. Sternberg (Eds.), *The Psychology of Gender* (2nd ed., pp. 242–268). Guilford Press.
- Pyke, K. D., & Bengtson, V. L. (1996). Caring More or Less: Individualistic and Collectivist Systems of Family Eldercare. *Journal of Marriage and the Family*, 58(2), 379–392. <https://doi.org/10.2307/353503>
- Reinhard, S. C., & Horwitz, A. V. (1995). Caregiver Burden: Differentiating the Content and Consequences of Family Caregiving. *Journal of Marriage and the Family*, 57(3), 741-750. <https://doi.org/10.2307/353928>
- Remtulla, Y., Charles, G., & Marshall, S. (2012). An analysis of responsibility, attachment security, and relationship efficacy among young carers. *Relational Child and Youth Care Practice*, 25(2), 49-57.
- Rivers, J. W., & Stoneman, Z. (2003). Sibling Relationships when a Child has Autism: Marital Stress and Support Coping. *Journal of Autism and Developmental Disorders*, 33(1), 383–394.
- Ronicle, J., & Kendall, S. (2011). Improving support for young carers: family focused approaches. Department for Education Research Report DFE-RR084. London, UK: Department for Education. doi:10.1037/e604732011-001
- Rose, H. D., & Cohen, K. (2010). The experiences of young carers: A meta-synthesis of

qualitative findings. *Journal of Youth Studies*, 13(4), 473–487.

<https://doi.org/10.1080/13676261003801739>

Russell, R. (2001). In sickness and in health a qualitative study of elderly men who care for wives with dementia. *Journal of Aging Studies*, 15(4), 351–367.

[https://doi.org/10.1016/S0890-4065\(01\)00028-7](https://doi.org/10.1016/S0890-4065(01)00028-7)

Sabogal, F., Marín, G., Otero-Sabogal, R., Marín, B. V. O., & Perez-Stable, E. J. (1987).

Hispanic Familism and Acculturation: What Changes and What Doesn't? *Hispanic Journal of Behavioral Sciences*, 9(4), 397–412. <https://doi.org/10.1177/07399863870094003>

Saunders, M. (2010). Working and caregiving: A comparison of employed and unemployed caregivers of older heart failure patients. *Holistic Nursing Practice*, 24, 16-22.

Schneider, D. (1986). *American Kinship: A Cultural Account*. Prentice Hall.

Schulz, R. & Czaja, S.J. (2018). Family caregiving: A vision for the future. *The American Journal of Geriatric Psychiatry*, 26(3), 358-363.

Schulz, R. & Eden, J. (2016). Family caregiving roles and impacts. In R. Schulz & J. Eden (Eds.), *Families Caring for an Aging America* (pp. 73-122). The National Academies Press.

Schumacher, K. L., Stewart, B. J., Archbold, P. G., Dodd, M. J., & Dibble, S. L. (2000). Family caregiving skill: Development of the concept. *Research in Nursing and Health*, 23, 191–203. [https://doi.org/10.1002/1098-240X\(200006\)23:3<191::AID-NUR3>3.0.CO;2-B](https://doi.org/10.1002/1098-240X(200006)23:3<191::AID-NUR3>3.0.CO;2-B)

Segall, M., & Wykle, M. (1989). The Black family's experience with dementia. *The Journal of Applied Social Sciences*, 13(1), 170–191.

<http://search.ebscohost.com/login.aspx?direct=true&db=psych&AN=1989-34187-001&site=ehost-live>

Sexton, A.E., Hayes-Conroy, A., Sweet, E.L., Miele, M., Ash, J. (2017). Better than text?

Critical reflections on the practices of visceral methodologies in human geography.

Geoforum, 82(1), 200-201.

Shahly, V., Chatterji, S., Gruber, M. J., Al-Hamzawi, A., Alonso, J., Andrade, L. H.,

Angermeyer, M. C., Bruffaerts, R., Bunting, B., Caldas-De-Almeida, J. M., De Girolamo,

G., De Jonge, P., Florescu, S., Gureje, O., Haro, J. M., Hinkov, H. R., Hu, C., Karam, E. G.,

Lépine, J. P., ... Kessler, R. C. (2013). Cross-national differences in the prevalence and

correlates of burden among older family caregivers in the World Health Organization World

Mental Health (WMH) Surveys. *Psychological Medicine*, 43(4), 865–879.

<https://doi.org/10.1017/S0033291712001468>

Shantz, C. U., & Hartup, W. W. (1992). *Conflicts Between Siblings*. Cambridge University Press.

Shifren, K. (2008). Early caregiving: Perceived parental relations and current social support.

Journal of Adult Development, 19(2), 11–121.

Shifren, K., & Kachorek, L. (2003). Does early caregiving matter? The effects on young

caregivers' adult mental health. *International Journal of Behavioral Development*, 27(4),

338–346.

Sieber, S. D. (1974). Toward theory of role accumulation. *American Sociological*

Review, 39, 567-578.

Siskowski, C. (2006). Young caregivers: Effects of family health situations on school

performance. *Journal of School Nursing*, 22(3), 163–169.

- Smyth, C., Blaxland, M., Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal of Youth Studies*, 14(2), 145-160.
- Sörensen, S., & Pinquart, M. (2005). Racial and ethnic differences in the relationship of caregiving stressors, resources, and sociodemographic variables to caregiver depression and perceived physical health. *Aging and Mental Health*, 9(5), 482–495.
<https://doi.org/10.1080/13607860500142796>
- Sprung, S., & Laing, M. (2017). Young carer awareness, identification and referral. *British Journal of Community Nursing*, 22(8), 398–406. doi: 10.12968/bjcn.2017.22.8.398
- Stamatopoulos, V. (2015). One million and counting: The hidden army of young carers in Canada. *Journal of Youth Studies*, 18(6), 809-822.
<http://dx.doi.org/10.1080/13676261.2014.992329>
- Stamatopoulos, V. (2016). Supporting young carers: a qualitative review of young carer services in Canada. *International Journal of Adolescence and Youth*, 21(2), 178–194.
<https://doi.org/10.1080/02673843.2015.1061568>
- Stamatopoulos, V. (2018). The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth. *Child and Youth Services*, 39(2–3), 180–205.
<https://doi.org/10.1080/0145935X.2018.1491303>
- Stern, S. (1996). Measuring child work and residence adjustments to parents' long-term care needs. *Gerontologist*, 36, 76–87.
- Stueve, A., & O'Donnell, L. (1989). Interactions between women and their elderly parents: Constraints of daughters' employment. *Research on Aging*, 11, 331–353.

- Szafran, O., Torti, J., Waugh, E., & Duerksen, K. (2016). Former Young Carers Reflect on Their Caregiving Experience. *Canadian Journal of Family and Youth*, 8(1), 129–151.
- Teh, Y. Y., & Lek, E. (2018). Culture and reflexivity: Systemic Journeys with a British Chinese Family. *Journal of Family Therapy*, 40(1), 520–536.
- Thompson, E. (2002). What’s Unique About Men’s Caregiving? In B. Kramer & E. Thompson (Eds.), *Men as Caregivers*. Prometheus Books.
- Updegraff, K. A., McHale, S. M., Whiteman, S. D., Thayer, S. M., & Delgado, M. Y. (2005). Adolescent sibling relationships in mexican american families: Exploring the role of familism. *Journal of Family Psychology*, 19, 512–522. <https://doi.org/10.1037/0893-3200.19.4.512>
- Van Volkom, M. (2006). Sibling Relationships in Middle and Older Adulthood. *Marriage & Family Review*, 40(2/3), 151–170. <https://doi.org/10.1300/J002v40n02>
- Viana, M. C., Gruber, M. J., Shahly, V., Alhamzawi, A., Alonso, J., Andrade, L. H., Angermeyer, M. C., Benjet, C., Bruffaerts, R., Caldas-de-Almeida, J. M., de Girolamo, G., de Jonge, P., Ferry, F., Florescu, S., Gureje, O., Haro, J. M., Hinkov, H., Hu, C., Karam, E. G., ... Kessler, R. C. (2013). Family burden related to mental and physical disorders in the world: Results from the WHO World Mental Health (WMH) surveys. *Revista Brasileira de Psiquiatria*, 35(2), 115–125. <https://doi.org/10.1590/1516-4446-2012-0919>
- Walter, U., & Petr, C. (2000). A template for family-centered interagency collaboration. *Families in Society: The Journal of Contemporary Social Services*, 81(5), 494-503
- Watt, G., Ibe, O., Edginton, E., & Whitehead, R. (2017). “Coping is difficult, but I feel proud”: perspectives on mental health and wellbeing of young carers. *Children and Young*

People's Commissioner Scotland. Retrieved from

<https://dera.ioe.ac.uk/28395/1/CopingWithCaring.pdf>

- Webster, L., & Mertova, P. (2007). *Using Narrative Inquiry as a Research Method: An Introduction to Using Critical Event Narrative Analysis in Research on Learning and Teaching*. Routledge.
- Weisner, T. S. (1993). Overview: Sibling Similarity and Difference in Different Cultures. In C. W. Nuckolls (Ed.), *Siblings in South Asia* (pp. 1–18). Guilford Press.
- White, C.L., Barrientos, R., Dunn, K. (2014). Dimensions of uncertainty after stroke: Perspectives of the stroke survivor and family caregiver. *Journal of Neuroscience Nursing*, 46(4), 233-240.
- Whiteman, S. D., McHale, S. M., & Soli, A. (2011). Theoretical Perspectives on Sibling Relationships. *Journal of Family Theory & Review*, 3(2), 124–139.
- Willyard, J., Miller, K., Shoemaker, M., Addison, P. (2008). Making sense of sibling responsibility for family caregiving. *Qualitative Health Research*, 18(12), 1673-1686.
- Wolcott, H. F. (1994). *Transforming Qualitative Data*. Sage.
- Yeh, H. C., & Lempers, J. D. (2004). Perceived sibling relationships and adolescent development. *Journal of Youth and Adolescence*, 33(2), 133–147.
- Zukow, P. G. (1989). *Sibling Interaction Across Cultures: Theoretical and Methodological Issues* (P. G. Zukow (ed.)). Springer-Verlag.
- Zuroff, D. C., Blatt, S. J., Sotsky, S. M., Krupnick, J. L., Martin, D. J., Sanislow, Charles A., I., & Simmens, S. (2000). Relation of therapeutic alliance and perfectionism to outcome in brief outpatient treatment of depression. *Journal of Consulting and Clinical Psychology*, 68,

114–124. <https://doi.org/10.1037//0022-006x.68.1.114>