

THE EXPERIENCES OF YOUNG CAREGIVERS OF OLDER ADULTS LIVING WITH  
COMPLEX HEALTH ISSUES

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## ABSTRACT

### The Experiences of Young Caregivers of Older Adults Living with Complex Health Issues

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The research regarding the experiences of younger caregivers is limited and this study is an attempt to understand the experiences of young informal caregivers of older adults with complex health issues. Using a grounded theory approach allowed for development of a theory that focused on the process, action, and interactions that shaped the experiences of the participants. Grounded theory research was conducted using one-on-one in-person interviews with two young caregivers to understand how they experienced caregiving for older adults living with complex health issues. This study revealed that these caregivers dealt with the challenges associated with caregiving and sustain themselves in their caregiving role by primarily utilising informal interventions, which were interventions that were outside of healthcare supports. Culture and family dynamics also affected the caregiver experience. This study highlights the need to examine existing caregiver interventions and expand our understanding of how to support caregivers, who are a diverse group with diverse needs. Caregiving is dynamic and is affected by factors outside of caregiving, thus interventions should be flexible and context-led to better meet the needs of caregivers.

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## DEDICATION

I dedicate this study to my Mother who always been and continues to be my role model and to whom I owe my curious nature and unending desire to learn.

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## **CHAPTER 1: INTRODUCTION**

Before I became or even realized that I was caregiver, I thought that a typical informal or family caregiver was an older person, who was a spouse or sibling, and was about the same age as the care recipient. I thought that since the caregiver was older that they would be at a stage in their life where they had more time to be a caregiver. This was even as I knew that I would be helping my mom as she got older, but I never thought that she would have to rely on another person in just about every aspect of her life, and so early in her life. My thoughts have changed since I began my journey as a caregiver nine years ago when I became my mother's caregiver in my mid thirties. My mother is living with two forms of dementia and the symptoms began to manifest themselves when my mother was in her mid sixties. I began to realize that I do not fit my description of what a caregiver looks like, and that some of my needs as a caregiver, and likely other caregivers, are also not being met.

I am a Black Canadian of African immigrant parents, a woman, a mature student and a caregiver. I am influenced by being a colonized-immigrant daughter and colonizer, and my intersectionality and identity has influenced my knowledge about my experiences as a young caregiver. As a child of African immigrants, I grew up with the teachings that family is more than just your nuclear family and includes my extended family. And there is no question that when the time came that I would care for any family member. I do not know whether the words helping, or obligation accurately describe what is meant by taking care of your family. Helping can imply that I am doing something as a favour, while obligations does not consider the fact that I want to help and that I would do so whether I felt obligated to do so or not.

An informal caregiver can be a family member, friend or neighbour who is providing unpaid care to a person because of that person's complex health issues, and is based on a

personal history between the person helping and the person who receives help (Fast, Keating, & Eales, 2001). Although informal caregivers have always existed, informal caregivers have become an integral part of the Canadian health system. It has been estimated that 13 million Canadians aged 15 and older, at some point in their lives, have provided care to a family member or friend with a long-term health condition (Sinha, 2012). In 2008/2009, 35% of people aged 45 or older reported caring for a senior with a short- or long-term health issues, with 73% aged 45 to 64, and 57% being women. Reports estimate that unpaid informal caregivers providing care for older adults in Canada are saving the healthcare system more than \$5 billion each year. Although 95% of caregivers aged 45 and older reported positive aspects of caregiving, 56% also reported experiencing negative experiences associated with caregiving (Turner & Findlay, 2012).

Caregiving is often seen as a burden or a sacrifice, and in some ways some caregivers do have to make sacrifices in their role as caregivers. In order to lessen some of the stresses associated with caregiving, caregivers need to have appropriate resources and supports. There are resources for caregivers and there have been recent improvements to some of these resources, including the addition of a relatively new program called Ontario's at Home Respite Care for Caregivers that, for qualified caregivers, provides fully covered respite hours for caregivers (Ontario Public Service, 2012-18). Unfortunately, some of these resources have not been accessible to all caregivers. For example, I was not allowed to attend a caregiver workshop because it was only open to caregivers who were 55 years of age or older, at the time I was in my thirties. In addition, some resources do not meet the specific and changing needs of the caregiver, whose role changes as the needs of their loved one change, while also not accounting for the changes that occur as caregivers pass through different life stages.

Meeting the needs of the caregiver, particularly those caregivers who are caring for their family members at home is especially important right now because there is a shortage of long-term beds, and not everyone needing placement in a long-term care facility will be able to get it. In Ontario, there are 627 licensed long-term care homes, both private and non-profit, providing 77,574 long-term stay beds for older adults requiring and eligible for permanent placement. As of February 2018, there were 33,080 people on the wait list for long-term care beds (Ontario Long Term Care Association, 2018). In addition, provincial governments continue to implement healthcare policies that are increasing the reliance on informal caregivers (Sawatzky & Fowler-Kerry, 2003). Western contemporary societies have been adjusting to major shifts in the global economy, which has resulted in changes at the economic, political and social levels. Governments have sought to reconfigure their responsibilities in the provision of public services, including in the healthcare sector. In the 1990s, the federal government reduced financial support to the provinces, the provincial and territorial governments responded by restructuring their respective healthcare systems. This resulted in a reduction in the number of hospitals and hospital beds as well as a reduction in the average length of stay in hospitals. In addition, provincial governments either increased centralisation or decentralised funding responsibility. This restructuring resulted in policies and actions, such as privatisation, rationalisation and devolution that were then used to reduce the role of government in the funding and/or delivery of healthcare services. The effects of these trends is the growth in demand for care in the home and community, which resulted in local health authorities who were unable to provide and the growth of private organisations, voluntary agencies and informal caregivers (Skinner & Rosenberg, 2006), which are continuing to affect us today. Whether the caregiver and care recipient are living together or not, meeting the needs of the caregiver through supports and services will help

to lessen some of the stresses for caregivers and allow caregivers to better care for their family members, while also taking care of themselves. This includes younger caregivers (under the age of 55), who may be in the role of caregiver for a long period of time.

This study focused on informal/family caregivers under the age of 55, capturing their experiences as caregivers of older adults living with complex health issues, including both the positive and negative factors associated with their caregiving role. Knowing how age and stage of life, as well as other factors affecting the types of resources that caregivers need, can lead to the development of supports and resources that better meet the needs of caregivers whatever their age and stage in life.

The key findings of the study indicate that the participant caregivers dealt with the challenges associated with caregiving and sustain themselves in their caregiving role by utilizing informal interventions. These interventions consisted of doing self-care, balancing their various roles and responsibilities and changing their communication strategies. By integrating these strategies, the participants were not only able to deal with new and ongoing challenges associated with caregiving but were also able to sustain themselves in their caregiving role as it became a permanent role in their lives. In addition, intervening conditions, including culture and family dynamics, affected these caregivers and how they sustained themselves.

## **CHAPTER 2: LITERATURE REVIEW**

In previous literature focusing on the experiences of informal/family caregivers, the core themes were made up of four general themes, which are the following: 1) the challenges associated with caregiving; 2) the rewards associated with caregiving; 3) the processes that caregivers use to sustain their roles as caregivers; and 4) the recommendations to better meet the needs of caregivers. There were two slightly different ways that the major themes were categorised. One included categorising these major themes as the adaptations and learnings that emerged from the caregivers experiences, and that helped them to shape care going forward; while the challenges and rewards associated with caregiving described the context of the care experience (Anderson & White, 2018). The other way that the major themes were categorised was as the experience of loss and grieving; adapting and coping to the new reality, and the short- and long-term impact of caregiving. While most of the literature had a broader approach when exploring caregiver experiences, a few focused on the effects of caregiving on the caregiver's personal life.

In all the reviewed studies, challenges associated with caregiving was either the primary focus of the study or emerged a major theme. Within the theme of challenges, a subtheme emerged which was realizing the endlessness of their role as caregivers, leading to many caregivers becoming resigned to the care responsibilities and dependency of their family member(s). This was accompanied by feelings of isolation and the perception that their lives were on hold (Hwang et al., 2017; Peacock et al., 2017; Sakakibara, Kabayama, & Ito, 2015; Sawatzky & Fowler-Kerry, 2003). A lack of control in their caregiving role was another challenge that emerged and was often related to the caregiver experiences of navigating the healthcare system (Hwang et al., 2017; Sawatzky & Fowler-Kerry, 2003). This included

decision-making and having to co-ordinate and communicate with multiple specialists (Peacock et al., 2017); a lack of support in transitional care (Giosa, Stolee, Dupuis, Mock, & Santi, 2014); the perception of “choice” when transitioning an older adult into long-term care (Konietzny et al., 2018), in addition to affecting caregivers as they tried to balance their caregiving and work responsibilities. This lack of control also affected caregivers in their personal life, including when trying find the time and energy for self-care (Campbell, 2010; Gui & Koropecykj-Cox, 2016; Konietzny et al., 2018; Mehta & Leng Leng, 2017).

Another challenge was that caregivers limited their utilisation of the healthcare system, which often led to caregivers maintaining their older adult at home for as long as possible, thus increasing their caregiving responsibilities with limited supports (Brémault-Phillips et al., 2016; Gui & Koropecykj-Cox, 2016; Hwang et al., 2017; Konietzny et al., 2018). The decline in wellbeing for the caregiver is another challenge (Brémault-Phillips et al., 2016; Brotman et al., 2007), which takes the form of a decline in overall health, financial instability (Campbell, 2010), and changes in family and social dynamics (Giosa, Stolee, Dupuis, Mock, & Santi, 2014; Peacock et al., 2017). The challenges associated with caregiving affected caregivers in various interactions and stages in their caregiving role, along with affecting other aspects of their lives, with caregivers experiencing overall feelings of stress, burden, and a lack of control.

Focusing on the challenges of caregiving can reveal not only how informal/family caregivers are affected and respond to these challenges, but also reveals the ways in which they can be better supported. But an unintentional consequence could be that the caregiver only sees it and experiences it as a burdensome role and may discourage some people from becoming caregivers themselves. In addition, the care recipient may come to view themselves as a burden

to their family members and not ask for the help that they need, further exposing themselves to risks associated with their complex health issues.

Familism refers to the “reliance on family for support, obligation towards family members, and use of relatives as referents” (Rozario & DeRienzi, 2008, p. 772), and studies have shown that familism beliefs of caregiving among African American women can lead to psychological distress. Rozario and DeRienzi (2008) found that caregivers following traditional familism values may bear sole responsibility of family caregiving. This implies choice in taking sole responsibility in meeting the needs of their loved ones. Although this is based on American research, I would suggest we consider the history of social welfare in Canada. Colonialism and racism were factors in the early development of social welfare, which was used to solidify white dominion (Tam, 2017). The discourse of deserving and non-deserving races is a socially constructed categorisation, which has resulted in the exclusion of Black and Indigenous people from social assistance (O'Connell, 2013).

I would suggest that traditional beliefs regarding caregiving were, and for some continue to be, the only choice available to ensure the care of a loved one because access to formal caregiving lacks equity, not only among Black women, but other racialized groups, poor people, undereducated people, and other marginalized groups. Um and Lightman (2016) found that there was a significant difference in receiving government funded home care between immigrant and non-immigrant seniors. Although these findings could not explain why immigrant seniors receive less home care from the government, possible reasons given included lack of information, linguistic and cultural barriers and practices. Existing gaps in accessing formal home care services by diverse senior populations indicate that immigrant seniors rely more heavily on family caregivers to meet their needs for home care (Um & Lightman, 2016).

African American communities are often dealing with social and economic condition, such as issues of oppression, racism, classism and sexism, that work against the ability of families to meet their basic needs (Simpson & Lawrence-Webb, 2009). Simpson and Lawrence-Webb (2009) examined African American grandmothers' perceptions of availability and accessibility of community resources to meet their caregiving needs. They found that these grandmothers would rely on family and community resources because they had sustained them over the years and provided a holistic approach; they also experienced inappropriate and unresponsive human services agencies; and they had limited options which resulted in them using alternative forms of assistance, such as extended family supports (Simpson & Lawrence-Webb, 2009). Thus, we must be careful when citing familism or cultural beliefs or traditions because it may lead to limiting the social resources to certain groups because it is assumed that they do not need nor want to use them.

Although much of the research focuses on the challenges of caregiving, research has evolved to a more balanced understanding of the caregiving experience (Anderson & White, 2018). With this move, the major themes that were revealed were the rewards associated with caregiving, the processes that caregivers use to sustain themselves in their roles as caregivers and recommendations to better meet the needs of caregivers. The rewards associated with caregiving was another major theme that emerged. Although not to the same degree as the other themes, rewards also played an important role in why sustaining the caregiving role was important and, in the recommendations, to support caregivers. One of the main rewards of caregiving was the preservation of family relationships, especially between the caregiver and care recipient. Despite the stresses experienced in caregiving, for some caregivers, caregiving moved past simply being a sense of duty to a gratifying experience (Brémault-Phillips et al., 2016; Campbell, 2010; Gui &



Koropecky-Cox, 2016; Sakakibara, Kabayama, & Ito, 2015). For some caregivers, having the physical and mental capacity to care for their family member, as well as personal growth through the development of caregiver skills, were also cited as rewarding experiences (Peacock et al., 2017).

Another major theme was strategies and resources used by caregivers to sustain themselves and to help them improve their flexibility in their role as caregivers. Strategies that emerged included cultivating personal meaning and motivations for caring; maintaining parental and family relationships, as well as systems of support, both within and outside of the family (Brémault-Phillips et al., 2016; Hwang et al., 2017; Mehta & Leng Leng, 2017). This also involved focusing on the caregiver themselves including living their own lives and self-care, and using caregiver services (Campbell, 2010; Mehta & Leng Leng, 2017; Peacock et al., 2017; Sakakibara, Kabayama, & Ito, 2015).

Research has suggested that self-care is an empowering way to reduce caregiver stress and improve their health (Pope, Giger, Lee, & Ely, 2017), but I believe that the concept of self-care can be troubled. Studies have found that caregivers who are experiencing high levels of stress are less likely to take care of themselves and instead engage in risky health behaviour (Pope et al., 2017), but risky to whom? Do caregivers experiencing high levels of stress have the ability in the moment to recognize that they need to take care of themselves? In addition, although caregiver supports exist, do all caregivers know about them, let alone have access to them? For caregivers to not only engage in self-care but also benefit from self-care, caregivers need to know that their loved ones are being well cared for, so that they can focus on themselves, thus a self-care plan for caregivers must include care plans for the care recipient. Self care can imply that it is the responsibility of the caregiver to care for themselves, but the caregiver needs

to be able to care for themselves, which requires resources and supports for caregivers in doing so. Thus, as an individualized concept, caregivers must be asked, “How can I help you to take care of you?”

Strength and resilience are often tied to the rewards of caregiving and the ways that caregivers sustain themselves in their caregiving role. Individual strengths are often associated with the qualities, assets and relationships that help us to continue despite the problems that we face. In a similar vein, resilience, which is fundamental to the strengths perspectives, is defined as a personal characteristic that allows a person to reduce the negative affects of social conditions on one’s daily life (Scott, 2013). According to Scott (2013) resilience has been attributed to successful caregivers. While resilience is attributed to successful caregivers, we must be careful because this can lead to the belief that it is the fault of the caregiver when they are struggling in their role as caregivers. Anderson and White (2018) suggest that fostering attributes like creativity and discovering a sense of accomplishment with respect to their caregiving role could promote the adaptive behaviour likely to allow a person to remain at home longer. This places the need to change and cope with caregiving on the shoulders of caregivers, which, like the concept of resilience, places the need for change on the caregiver and can also lead to blaming the caregiver for being unable to cope with their role as a caregiver. Similarly, familism may interfere with the caregivers’ help-seeking behaviours because they blame themselves for not being able to manage in their caregiving role or because of a sense of family obligation (Rozario & DeRienzi, 2008).

Recommendations that would better support caregivers in their caregiving role emerged as the final major theme. Recommendations included providing resources for caregivers, such as education and training for the caregivers themselves to build their capacity as caregivers.

Another recommendation was providing training for health care professionals (HCP) to meet the needs of caregivers as well as improve their interactions with caregivers (Brémault-Phillips et al., 2016; Brotman et al., 2007; Sakakibara, Kabayama, & Ito, 2015). In addition, social and healthcare systems must work to meet the needs of caregivers. This would include improved and increased access to resources, system navigators and more responsive caregiver centered systems (Brémault-Phillips et al., 2016; Brotman et al., 2007). These recommendations could help reduce caregiver stress by meeting the immediate needs of the caregiver, but also allowing caregivers to consider the resources they may need in their ever-changing role as a caregiver, both in the short-term and long-term. They also allow caregivers to think about what their caregiving role might look like in the future and what resources they may need then.

An unintentional consequence of policies that emphasize the role of informal caregiving is reinforcing the belief that informal caregivers must rely on their own limited resources to meet the needs of their loved ones. This reinforcement then legitimizes the low demand and supply of government services (Rozario & DeRienzi, 2008), which often runs in line with a neoliberal agenda, where increased self reliance has replaced state provided social welfare (Brown, 2006). The result of moving past only focusing on caregiving at the individual or micro level and broadening it to a societal level could be a better understanding that supporting caregivers can be more cost effective than not supporting caregivers. A focus on supporting caregivers at the societal level is also more proactive, rather than reactively dealing with the consequences of not supporting them. For example, when dealing with certain health issues, some older adults end up going in and out of hospital because they are discharged from the hospital and sent home; however, once the return to home, there is a lack of home supports or the supports are too expensive which results in the individual returning to the hospital. Proactively supporting

caregivers before major issues occur could help to alleviate some of these issues. Thus, excluding societal factors that are affecting both the caregiver and the care recipient, can result in increasing reliance on these caregivers as well as a continued lack of support for them.

Although the primary focus has been the various challenges associated with caregiving, Anderson and White (2018) highlight the interplay of rewards and challenges, where it was by experiencing certain challenges that caregivers were then able to recognise or develop some type of reward. For example, the interplay between challenges and rewards included the interplay of the concept of preparedness, which included actively acquiring knowledge or skills, and feelings of being overwhelmed. Caregivers were often able to develop rewards from the close relationship between themselves and the family member that they were caring for, and from the opportunity to do caregiving (Anderson & White, 2018). Thus, in some way challenges could not only be tied to some rewards, but to coping and recommendations, all of which could help informal/family caregivers remain in their caregiving role. The overall caregiver experience was described as life changing and consuming for the caregivers, which included the broad impacts on the health of informal caregivers (Sawatzky & Fowler-Kerry, 2003).

Unless purposively excluded, most of the participants in these studies were older caregivers, with caregivers being the spouses of the carer or older aged adult children. Only one study indicated that most of the caregivers were relatively young, with the caregivers age range of 33-72. One study included participants aged 23-31, but these participants were not caregivers at the time of the study but spoke of their future caregiver responsibilities when they would be expected to care for their aging parents (Gui & Koropecj-Cox, 2016).

Except for the study comparing married and single sons (Campbell, 2010), in all the other studies most participants were women caregivers. The 'marital status' of caregivers was only

included in four of the studies (Brotman et al., 2007; Campbell, 2010; Mehta & Leng Leng, 2017; Peacock et al., 2017). In addition, the occupation and financial stability of the caregivers were included in demographic information of the caregivers in three of the studies (Hwang et al., 2017; Mehta & Leng Leng, 2017; Rozario & DeRienzi, 2008). A few studies did acknowledge that many of the participants were financially comfortable or better (Hwang et al., 2017; Mehta & Leng Leng, 2017). Thus, less affluent caregivers were excluded from the studies. Most of the studies were done in urban settings, which excluded caregivers living in rural areas.

Two studies explicitly stated the ethnicity of the participants (Gui & Koropecj-Cox, 2016; Rozario & DeRienzi, 2008). A few of the studies cited a lack of ethnic diversity as a limitation since most of the participants were Caucasian (Brotman et al., 2007; Konietzny et al., 2018; Peacock et al., 2017), while ethnicity and/or the racialization of the caregivers were not noted in the remaining studies. Although one study did look at lesbian and gay older adults, LGBT caregivers were not directly focused on (Brotman et al., 2007). In addition, the Campbell (2010) study did not mention whether the single men were heterosexual or whether they identified as LGBT2+. In addition, the married men of this same study were married to women. Thus, excluding men who did not fit into these two very narrow boxes, including men who identify as being LGBT2+, and those that were not in heteronormative relationships. Lastly, according to Brotman et al., (2007) not all people providing informal care would self-identify as caregivers because they did not see themselves as caregivers.

Interventions are based on those people that are involved in the studies used to develop them. The exclusion of certain groups of caregivers in studies on caregivers, results in the development of interventions that work well for certain caregivers and may not be best suited to help those excluded caregivers and their unique situations. Increasing the diversity of caregivers

involved in future studies can work towards developing interventions that are better able to meet the needs of the diverse group of caregivers that exists.

My research focuses on capturing the experiences of informal caregivers, 55 years of age and younger, who are caregivers for older adults living with complex health needs. Younger caregivers are a demographic that had very limited participation in the studies reviewed. The needs of caregivers may vary, including according to different stages of life and financial stability level. For example, caregivers who are retired and those that are working will likely have some differences in their caregiver support needs. Exploring the experiences of younger caregivers is especially important because it is likely that they will be caregivers for a longer period, affecting them as they move into different life stages, and may also be caregivers to more than one person.

### 3: METHODOLOGY

This study is grounded theory research and is meant to explore the experiences of caregivers aged 55 and under caring for older adults living with complex health issues. The research question is; *what are the experiences of young caregivers of older adults living with complex health issues?* First described by Glaser and Strauss more than 50 years ago, grounded theory was, “designed to create theories that are empirically derived from real-world situations” (Oktaý, 2012a, p. 2). Grounded theory allows for the development of theory that focuses on a process, an action or an interaction that is shaped by the experiences of the participants (Creswell & Poth, 2018). More specifically, constructivist grounded theory includes the perspective that situates knowledge in time, space and context, while also considering my construction of the emergent concepts (Charmaz, 2017). Since grounded theory method was developed from an interaction between theory and practice, grounded theory can produce theories that can guide social work practice. Thus, theories that are directly applicable to practice can be used to develop theoretically based interventions (Oktaý, 2012a). In addition, both social work and grounded theory are rooted in symbolic interactionism, pragmatism and the ideals of the Progressive Era, which make the procedures and assumptions of grounded theory familiar to social work researchers (Oktaý, 2012a).

One of the strengths associated with grounded theory is that it integrates relativity and reflexivity throughout the research process by bringing the my role and actions into view (Charmaz, 2017). In addition, the theories that are generated take into consideration the context of the study, thus providing flexibility in being able to address real-world issues (Creswell & Poth, 2018). One of the limitations or challenges of grounded theory is that I must work at setting aside theoretical ideas and notions to allow for substantive theories to emerge. Another

limitation is the I must be able to “recognise when categories are saturated and when a theory is sufficiently detailed” (Creswell & Poth, 2018, p. 88), which can make it difficult to predict the length of the study. Thus, I may not have the luxury of continuing the study until saturation is reached (Oktay, 2012d).

It is important to note that I am a young caregiver and therefore as a researcher and caregiver, I am an “insider-outsider” and have a vested interest in the research that I am doing, thus my research is subjective (Sky, 2016). I am a young caregiver of an older adult living with complex health issues and therefore have some insider experiential knowledge about this topic, and it is my experience within this research topic that has influenced me to explore others’ experiences and their own intersectionalities, and to produce more knowledge on the experiences of young caregivers. This also raises the potential issue of selective identity, where I focus on my social location similarities with the participants, while ignoring my privileges and power, especially as the researcher (Langhout, 2006). Although I am the daughter of colonised parents, I am also living on Indigenous land, where Indigenous people continue to be marginalised and reconciliation more a noun than a verb. Because my epistemology is also based on my experiences of being a child of colonized parents as well as a colonizer myself, I must implicate my role in colonizing Indigenous people, and marginalizing others.

To respond to these epistemological issues in the context of my research, Baksh (2016) suggests that we critically examine social discourses and the accepted positions of what is known. Using a constructivist grounded approach helps to ensure that generalizations are not neutral and that the aim is an interpretative understanding of the shared experiences. In addition, constructivist grounded theory understands that there are multiple realities and takes into consideration my subjectivity (Charmaz, 2017). Constructivist grounded theory allows me to



challenge dominant research processes and outcomes, especially by involving the participants and co-constructing the theory with them (Potts & Brown, 2015).

Langhout (2006) reminds us that although the end goal is to capture the experiences of young caregivers that there are also process goals. This includes continuing to be reflexive throughout the research process by continually situating myself; evaluating my subjectivity and relational dynamics; and reducing the risk of reproducing oppression and injustice (Sky, 2016). This is especially important since oppression also occurs in various activities and social practices, including in and through my research (Baksh, 2016; Potts & Brown, 2015).

This research is considered as a way of challenging the dominant discourses regarding aging and informal caregivers, by allowing not only the research itself to disrupt the status quo, but also allowing the personal experiences of the caregivers themselves to speak out and disrupt (Sky, 2016). I continue to work at checking myself, which requires constant reflection and critique. I am choosing to recognize different experiences, which will enable me to be purposeful in my anti-oppressive actions (Potts & Brown, 2015). My personal epistemology includes considering the context and subjectivity of the experiences that are shared with me and knowing that experiences and knowledge is multiple and diverse. Within this research, I stand with my participants to better understand the experiences of young caregivers, the challenges they experience and to explore interventions that best support them. Thus, allowing for more inclusive caregiver interventions to be developed and implemented.

While recognizing that ground theory requires researchers to suspend theoretical constructs about our topic, I wish to share some of the theories that influence my epistemology which include anti-oppression or critical social work, feminism, and anti-racism. Anti-oppression theory allows me to extend my focus from personal problems to social relations and how they

contribute to the problems that people are facing (Hicks, Fook, & Pozzuto, 2005), which are also better understood when considered alongside the broader notions of power and domination (Campbell & Baikie, 2012; Parker & Aggleton, 2003). It also allows me to acknowledge the role that social work has had in oppressing others, while also helping me to be reflective and reflexive in my research and practice (Hicks, Fook, & Pozzuto, 2005).

Although I am influenced by feminist theories, I am also critical of feminism for who is included and who is excluded. As a Black woman, I am heavily invested in anti-racist theories that not only expose the endemic and often invisible nature of racism. Anti-racism also highlights intersectionality, which allows me to understand the ways in which multiple forms of inequality converge to create unique obstacles that need to be understood outside of conventional ways of thinking about oppression (Crenshaw, 2016). As a critical social worker, these theories allow me to bring inclusivity and participation into my research and practice by challenging social structures and social relations (Hicks, Fook, & Pozzuto, 2005). These theories highlight the forces that create and support inequality, oppression, and injustice, with the goal of “identifying the multiple possibilities of the present in order to contribute to the creation of a more just and satisfying social world” (Hicks & Pozzuto, 2005, p. xi). These are some of the theories that influence my epistemology and will in turn allow me to work towards equality, social justice and social transformation.

## **Methods**

The study used informal groups to recruit participants, as well as the snowballing technique. Using the in-person or over the phone recruitment method, I contacted informal/family caregivers caring for older adults living with complex health issues in my network and sent potential research participants a recruitment email as an invitation to join this

study. In addition, if anyone within my network knew any caregivers under the age of 56, I sent these potential research participants a recruitment email (see appendix A), through my network contact, as an invitation to join this study. The recruitment email had my contact information, and potential participants who decided to take part in this research contacted me through the contact information provided in the email. I briefed potential participants about the research and its requirements; their rights and responsibilities; and informed them that they had the option of not answering a question, withdrawing their data, or opting out of the study without consequence. If the participants felt they could continue with the research, I invited them to the study. The participants signed the consent form after which the study commenced (see appendix B).

### **Sample**

I interviewed two informal caregivers in Toronto. The participants were supposed to be under the age of 55, caring for an older adult, aged 65 or older living with complex health issues. The participants were supposed to have been providing care for at least the six months prior to the commencement of the study.

Data was collected using one-on-one semi-structured grounded theory interviews that lasted 2-3 hours. An interview is a social interaction based on a conversation, where knowledge is constructed between the interviewer and interviewee. They allow me to attempt to understand the participants point of view and meaning of their experiences (Creswell & Poth, 2018). The interviews followed a semi-structured approach, which consisted of open-ended broad questions, which allowed participants to narrate and explain the significance of their experiences (See appendix C). Prompting questions were used to ensure consistency among interviews, and

probing questions were used to dig deeper and get clarification (Padgett, 2017; Stone & O'Shea, 2013).

Most of the challenges associated with qualitative interviewing are mechanical in nature, and include the ability to create good instructions, dealing with sensitive issues, and developing transcriptions (Creswell & Poth, 2018). Additional challenges include maintaining a one-sided conversation, truthfulness, incompleteness, and the gap between what people do and what people say (Padgett, 2017). As a researcher, I must also reflect on the relationship between me and the participants, including the existing power dynamics. By attending to the power dynamics, I can work to lessen the power differential between me and the participants. Participants who chose to 'opt-in' were able to review the interview transcripts and make edits. In addition, participants were reminded that they could access the final report at Ryerson's digital repository. While collecting data, I audio recorded the interviews and took notes to gather information from research participants. I personally transcribed and coded the data collected.

The qualitative grounded theory approach was employed in analyzing the data. The data was transcribed immediately after the interview, which was meant to maintain the emotional and contextual content of the raw data (Creswell & Poth, 2018). I then sent the transcribed data to the participants for authentication, to those participants who opted in. Files were then created from the transcribed data.

I read through the participant's data; created codes; and made additional notes. I developed codes through open coded using line-by line coding, which were then grouped into broader categories and concepts (Okta, 2012b). Open coding allowed me to develop codes from this data, including substantive codes which used the words from the participants and closely reflect the raw data. When the name of the codes or themes are actually in the data, the codes are

known as “in vivo” codes or themes (Oktaý, 2012b). The concepts and categories that were developed using open coding were further explored using axial coding, which moved to verifying concepts and their relationships to each other (Oktaý, 2012c). Ideally, data would continue to be gathered until saturation of the core category was reached (Oktaý, 2012b). In this study, saturation could not be achieved because of the limited number of participants and time constraints. Throughout the analysis of the data, memoing was also used to record ideas, questions, and thoughts, which allows for key components of grounded theory to be integrated, as well as comparisons to be made between interviews (Oktaý, 2012b). Selective coding was used to integrate and refine the theory that was developed in the open and axial coding stages and involves identifying the “core” category, which was then related to other important categories and concepts. In addition, selective coding also involved the review of the theory for completeness, internal consistency, and logic (Oktaý, 2012c).

#### **4: FINDINGS AND DISCUSSION**

This research study sought to uncover the experiences of younger informal caregivers, under the age of 55, caring for older adults living with complex health issues. Throughout the process of conducting this research, several explanatory themes emerged. Academic rigor was maintained by utilising an in vivo approach for data analysis and coding, and where whenever possible an effort was made to use the participant's own words to delineate themes. In vivo themes were cited in quotation marks, such as "And the time demand of it has been a challenge," to highlight participant voices, while themes that I labelled are without quotation marks. The emergent themes dealt primarily with the experiences of identifying the interventions enacted by the participants in dealing with the challenges associated with caregiving. The data suggests that there are interventions that are both common and unique to each of the caregiver participants. Intervening conditions affected their caregiving experience in both positive and negative ways, with cultural norms having the most significant effect. Context as well as flexibility, which take into consideration intervening conditions, should be incorporated into new and existing interventions to better meet the need of the caregiver and to help sustain them in their caregiving role.

The two participants recruited for this study differed in many ways. Paige (name changed to protect identity) identified as a woman, a mother, an undergraduate student, and was 33 years old. Paige is one of two primary caregivers to her grandmother and has been doing so for the past four years. Her grandmother, aged 94, is living with several complex health issues, including cancer, diabetes and hypertension. Although Paige does not live with her grandmother, her grandmother requires a lot of help. Sarah (name changed to protect identity) aged 46, identified as a woman, works professionally as a personal support worker, and is a caregiver to both her

mother (aged 76) and father (aged 77), both of whom are living with several complex health issues, including chronic obstructive pulmonary disease (COPD) and dementia. Although both parents are functional, Sarah lives with them and has been their caregiver for the past two years. All participant quotations were entered verbatim as written by participants in their transcripts to emphasise that participant voice was surfaced and valued. As such, normative forms of speech, spelling, capitalization, punctuation and grammar were not imposed.

The emergent themes in this study are organised according to in vivo participant accounts whenever possible and are positioned in such a way as to describe the caregiver experience. Moving from the participants' experiences of the challenges associated with caregiving to dealing with these challenges, the emergent themes construct an alternate way of dealing with the challenges associated with caregiving. Although the emergent themes are similar to existing themes associated with caregiving, the focus differs from existing themes in that the caregiver participants relied more on informal interventions and less so on formal interventions, thus focusing on interventions outside of the health care system. Formal support includes services provided by professional, trained, employed, individuals who are typically paid for their work, such as personal support workers (PSWs) or facilities such as a long-term care facility (LTCF). Informal support includes the support provided by their social network and community, which includes family, friends and neighbours (Shiba, Kondo, & Kondo, 2016). Basic needs, such as personal care and grooming, eating and food preparation, and mobility and transportation, as well as other needs can be provided through formal supports, informal supports or a combination of the two.

### **Dealing with the challenges associated with caregiving**

The core theme that emerged was dealing with the challenges associated with caregiving (see Table 1), which was an active process that required acknowledging and dealing with these challenges. This theme helped to reveal how caregiving is not static and that there is no one way to do or be a caregiver; instead caregiving requires flexibility and changing tactics as the circumstances associated with caregiving change. The core theme consisted of two major themes, the challenges associated with caregiving, and sustaining one's self as a caregiver as challenges arise. The challenges associated with caregiving were prevalent throughout both participant's accounts, allowing us to explore the challenges associated with caregiving at different stages of caregiving and as the caregiving role changed. The second major theme of sustaining yourself as a caregiver revealed how participants came to understand that sustaining themselves as caregiver requires doing self-care, as well as changing the way that they had been doing caregiving, especially as it became a permanent role in their lives.

Table 1: Emerging Themes

Dealing with the challenges associated with caregiving	
Challenges associated with caregiving	Sustaining yourself as a caregiver
• Becoming a caregiver	• Self-care
• Formalising caregiving	• Balance
• Caregiving becomes permanent	• Communication

### **Challenges.**

#### ***Becoming a caregiver***

Challenges was the most prevalent major theme that emerged, and one of the first subthemes that emerged were the challenges that occurred when caregiving began. A prior relationship existed between the participant and the person that they were providing care for,



which included, as Paige stated, “helping out” every now and then. The participants first became caregivers when their loved ones had a major health crisis, such as developing pneumonia or having a major fall. Paige shared:

But it just came to be that she fell, and then she became afraid to fall. So she needed assistance more not because she couldn't do the things she was doing before, but because fear just gripped her, and she felt that it wasn't safe. So at that point, we came up with a schedule within the families.

These challenges consisted of learning how to be a caregiver, learning their caregiving responsibilities and gaining knowledge about the health issues that their family member(s) was/were living with. These caregivers began to provide care, while relying on a few other family members to help.

One of the consequences associated with the challenges of caregiving when it first began was the need to include their caregiving role in their daily/weekly schedules to ensure that their loved one's needs were being met. This included having to prioritise caregiving over other responsibilities, not taking as much care for themselves, and trying to maintain their loved one's autonomy especially when communicating with their loved ones. For example, Paige shared that “you have to do this dance, because she likes to remind you that, you know, my mind still works, you don't get to tell me what to do.” They also both shared that they often felt “frustrated.” “overwhelmed,” and as Paige put it, “tapped out”, with their caregiving role. Although they may have been helping their loved ones before becoming an informal caregiver, it was perhaps viewed as temporary and that their loved one's would recover. By considering it as a temporary role, the care that was being provided may have been more reactive and less proactive, which

would not necessarily prepare them for the reality of their loved ones not recovering fully, that caregiving would increase instead of decrease, or that their caregiving role was ongoing.

### *Formalising caregiving*

As caregiving continued and moved passed being temporary, the participants realized that to provide better care, caregiving needed to be more structured. Another subtheme that emerged was the formalization of the caregiving that was being provided. The consequences of formalising caregiving included knowing how to better care for their loved ones; knowing that their loved ones' needs are being met and having to interact with the health care system and health care professionals on a regular basis. The caregivers now had to add caregiving to the time management and time demands, resulting in them having to allot more time to caregiving and thus had less time for their other roles and responsibilities. They also had to acquire knowledge of how to better care for their loved ones, including what worked and what did not.

One of the more difficult challenges that the participants had to deal with was the change in the relationship they had with their loved one, one primarily being that of a caregiver and care recipient. Paige shared:

Or if I go, another thing that I didn't even think of ahead of time, is if I go to her house, and all I'm going to do is what needs to be done. And I'm not there to spend time and be social or whatever. Um, what goes with that. And the feeling like when did this switch to me showing up for a job to be her PSW, um as opposed to just her granddaughter who's spending time with her and doing some things while I'm there. And she notices that difference. So sometimes when I'm going I tell her ahead of time now, mama you know, like today, I'm really crunched for time, I have an exam tomorrow that I need to review for, I'm going to come in whatever you need done, just think about what

you need done in the house, or what, if you need me to pick up groceries or whatever, and prepare ahead of time because I realized that when I go I feel bad that I'm just rushing in rushing out now then she's like, she literally said it one day, she's like, you gonna come in like PSW, you know, I'm not even grand Pitney them.

Although they were spending more time with their loved ones, visits moved away from visiting to spend time with their loved one to more caring and task-oriented visits. Paige stated that "...when she got more sick, the schedule pretty much stayed the same." Having to formalise caregiving was one of the first steps in acknowledging that their caregiving role was more than dealing with episodic health issues and now included ongoing declines as well as permanent health issues and comorbidity.

### ***Caregiving becomes permanent***

On caregiving becoming a permanent role, Paige shared:

I would say first, really let it soak in, like, actually assess, like, what that means. Um, but also remind yourself that usually before it becomes permanent, you are doing it anyway. Um, because if you just think about the permanency of it could seem just completely overwhelming and too much. But when you realize that you'll just be doing what you've been doing. It makes it more manageable, again, in my opinion.

One of the most important subthemes that emerged were the challenges associated with caregiving when caregiving became permanent, which then required the participants to figure out what they needed to be caregivers for the long run. Caregiving moved from a temporary role to a more permanent role when the participants realized that their loved ones' recovery of ability was not to levels of ability before the health crisis; that their loved ones were slowing down; and that

they needed more help, especially when it came to the activities of daily living (ADLs). Sarah shared:

Ah, actually even before my father got ill, because I've always been the one that people kind of went to when they needed help. And I was always willing to help, I was always willing to assist in any way that I can. So pretty, I would probably say pretty much all my life, I've been like that.

It is interesting to note that when they were looking at whether they were able to be caregivers on a permanent basis, both Sarah and Paige realised that they had been providing some type of care long before they understood that they were informal caregivers.

The consequences of caregiving becoming permanent are like the challenges associated with formalising caregiving but now must be considered on a permanent basis. This included having to consider their role as caregiving when making decisions regarding their other roles and responsibilities; and understanding that their caregiving roles and responsibilities would increase over time. Another consequence was that in formalising caregiving, these caregivers had to deal with little help and support from other family members. Sarah shared:

I had to ask him? Yeah, yeah, I had to,... Well, I told him, I said, I can't do this by myself. Like I said I can't be the one always running around because I have, I have a job to do. I work and my work is caregiving, you know, and I said, I can't do it all.

Thus, the caregivers also experienced resentment in having to do caregiving while seeing other family members do from very little to no caregiving. These difficulties of getting help on a permanent basis also led to feelings of resentment on the part of the caregivers.

It also affected the caregivers on a personal level by bringing forth the decline of their loved ones. They also had to watch their loved ones deal with the stigma associated with the

health issue(s) that they were living with, and deal with stigma themselves, as it related to them being caregivers. Sarah shared “I think there's a kind of, like a stigma, of people who look after their parents.” Caregiving was considered more than just a job, since being a caregiver was more than an eight-hour shift. On a professional level, prioritising caregiving affected the caregivers’ ability to work outside of the house, whether it is through a reduction in the number of hours they were able to work or choosing to work or go to school while also being a caregiver. Paige shared:

Um, so, when it's a job, you can call in sick. Um, when it's somebody that you love, and you want to make sure is okay, you're pushing through and going, even if that day, you're just like, I'm exhausted, I just want to sleep in.

The challenges associated with stepping into the caregiving role affected them on a personal level, their relationships with the person(s) they were caring for as well as their relationships with family members outside of the caregiving relationship. As they came to understand this caregiving role was becoming permanent they realised that for them to continue on as caregivers meant that not only would they continue to have to deal with challenges as they arose, but that they would need to develop strategies that would sustain them in their role as caregivers.

### **Sustaining yourself as a caregiver**

Sustaining themselves in their caregiving role was another major theme that emerged and revealed how the participants managed in their caregiving role, which allowed them to sustain themselves as caregivers, especially as they came to understand it as a permanent role in their lives. The three subthemes that emerged were self-care, balance, and communication.

### ***Self-care***

For these caregivers, becoming a caregiver was not a choice, instead it was just part of what family does for family. Knowing that they were not only willing to be caregivers but were also willing to continue to be caregivers on a permanent basis, motivated the caregivers to look at how they were going to deal with the challenges associated with caregiving, thus allowing them to manage and sustain themselves in their role as caregivers. This was especially important as both caregivers expressed that they were feeling “overwhelmed,” “exhausted,” and that they could no longer, as Sarah put it, “do it all”. Self-care emerged as a subtheme, and although there were commonalities between the participants there were also differences in the way that they each did self-care. Some of the ways that the participants did self-care was to take time to take care of themselves, both physically and mentally. For example, When the caregivers realised that they couldn’t do caregiving, both on an episodic and permanent basis, they would ask for help from other family members. Sarah must remind her brother by saying, “But, you know, I have to like, Hey, don't forget, you need to come by and you know, help out and stuff like that.” For Paige, moving past only relying on the other caregivers and getting other family members to help has become an important tool for her. She explains:

Oh, we'll try, we'll do it when we can, or whatever, we made a list of those people. And, as opposed to call in the other ones, so as opposed to my cousin calling me, if she can't make it on her day, the order now is to go through those people that aren't there regularly, I find that that makes a big difference. Because then I'm not doing my days and somebody else who's full time and then ended up there every day. I'm getting the balance of Okay, like, even if she can't make it or that I have the ability to go through these 12 people to say, maybe one of you guys could make it today, my grandmother's never gung ho because she's gotten used to the three of us that are there on the regular. Um, but then

we just remind her mama like when you ask him about this particular person, now you get to see them and figure out what's going on in their lives and stuff like that. So I find that that is probably lately, the biggest tool and help is the backup list.

Another way in which both caregivers did self-care was to engage in light entertainment. Paige shared, “I’m late me, I have taken into watching a random-ish on Netflix, or the computer or whatever, just anything, pretty much, um, and staying away, actually, from stuff that tend to be super heavy.” While Sarah shared:

I like to play Fishdome on my phone, fishdome, its a game ...Like, you know, like you say, you don't have to think, you know you just focus on this. That's pretty much it. I just have to think about, you know, you know, finishing the game or the level.

Being able to engage in light entertainment allowed Paige and Sarah emotional escape and acted as a distraction from caregiving.

One of the most important aspects of self-care for the caregivers was getting support for themselves. The caregivers divided this into two groups. The first was support from friends who were also caregivers and provided understanding and a network of support. The other group consisted of friends who were not caregivers themselves, and who, at times, provided for Paige, “a distraction” from caregiving and allowed Sarah to have “a social life.” The support from friends allowed them to acknowledge to others but more so to themselves, all that they do as caregivers, the sacrifices that they have had to make to be caregivers, to feel anger, and to vent their frustrations. Paige shared: “Yeah, that you're permitted to feel shitty sometimes. And, oh, on those days, when it feels like my patience is not like the best with my grandma to realize that I'm human.” Although non-caregiving friends were considered a “distraction,” Paige noted that

“sometimes they are helpful and sometimes harmful,” because they did not always understand or acknowledge the stresses of being a caregiver.

Self-care was also achieved by the participants in unique ways. Paige shared:

I'm, like I said, Christian, so that helps a lot. Lately, there's been some shifts that have happened. So that kind of complicates things with my grandma, because we don't necessarily agree on everything on like, what being Christian even means anymore. Um, so but that's definitely still at the core of my resources is the ability to just sit down and pray or to read my scripture, or to go to church less now than it was before. And just the amount of wisdom and experience that she's had in her life. Being there in a caregiving role allows her to pass on a lot of knowledge, and just experience.

Her Christianity allowed her to have a deep religious connection with her grandmother and helped to ensure that she and her grandmother connected in a way that was more reciprocal. Thus, expanding the dynamics of their relationship past that of caregiver and care recipient.

For Sarah, getting a dog allowed her to get out of the house on a regular basis, and helped to “alleviate anxiety and the depression.” She shares the following:

Even when I was in my, my therapist told me a good idea was to get a pet to because they do help alleviate anxiety, and the depression. When I got my dog, wow, what a difference not just for me, but for the entire family. And it was like bringing an angel into the midst of this chaos. And I think I think that actually was really hard. Why my mother started to get feel a little bit better. Mind you, you know, this was last year when she was hurting her back, but I don't think she would have gotten through it without that dog. Because he was actually a constant companion...And even though it's



like, you're still a caregiver, but it's still it is a complete joy, and you take him out for walks and, you know, he looks at you and there's like, you can't do anything wrong, you know.

Not only did getting a dog help her, an additional benefit was the positive effect that getting a dog had on her mother.

Self-care also involved sharing caregiver responsibilities. Participants recognised that they were either doing the caregiving alone or there were only a few people providing caregiving on a regular basis. Sharing caregiver responsibilities included getting other family members to help with caregiving; distributing caregiving tasks among primary caregivers or those involved in providing care; creating backup caregiving protocols; and knowing who was able and willing to help and who was not. Sharing caregiver responsibilities also allowed the participants and other family members to take on tasks that they felt they had the skills to do or were willing to develop the skills to be able to do. For Sarah, this meant that her brother was responsible for the outside work and tasks that required heavy lifting. Sarah shared what her brother does:

A lot of more of the laborous is stuff, lifting, you know, painting, like we're going to be painting, so he's gonna be painting. We had we had the veranda we rebuilt the veranda.

So he did that, with my God, brother. So my brother, my God-brother does come in and help as well. And yeah, so things like I like the heavy work like.

When she's not available Sarah also shared that, "If they need anything, they can just call my brother." For Paige, this meant that the two secondary caregivers, her mother and aunt, were responsible for grandma's personal grooming (excluding bathing), while all the caregivers did the cooking and cleaning. In addition, for Paige, "the biggest tool and help is the backup list,"

which allowed the primary caregivers to know who they could call when they needed additional help.

When it was difficult to share the caregiving responsibilities in a more equitable way, Sarah and Paige expressed frustration with not only the other family members “not helping” but also with the family members that they were caring for, who did not always acknowledge nor accept the help that they were providing. Paige shared:

You weren't there, you know, and I wouldn't say it to her, but I'm like, why am I doing the most but like when it comes to the grand scheme of things of what you've done for everybody in the family, I'm at the bottom end of that list. You know, like, there are some people that I have a cousin that, like now he stayed. Well, when she was in the hospital, he was staying in her apartment. So he's still there, but he didn't even go see her in the hospital. It was just like 'k like, and when he's there, he's not doing anything. You mean? Like he's not doing any kind of caregiving anything? And then like, how can you like, take so much and give so little? Um, so just dealing with that is a challenge.

Paige spoke about the importance of sharing caregiving responsibilities with those family members willing and able to participate in the caregiving, but she also noted that it was difficult to simply ask others to help. Paige shared:

And just sometimes like allowing myself to make the calls to the people that could step in, that's a challenge because to you'll hear no from like the first five and you're just like, no, forget it. Like I'll just go and probably be less stress to just go myself then to try to figure out which one of you guys are in the mood today.

Being able to share caregiving responsibilities helped the participants see and accept their caregiving role as a permanent one and helped to maintain consistency in the caregiving that was being provided, while also allowing them to get other people to do what they could not.

While there were both similarities and differences in the ways in which the participants did self-care, self-care played an important role in helping to ensure that the participant caregivers were able to continue in their caregiving role by allowing them to make time and space for physical and emotional self-care. This was especially important, as caregiving became a permanent role in their lives and changed as the needs of their loved ones increased.

### ***Balance***

Balance as a subtheme, emerged in many different aspects of caregiving, and revealed the ways in which the participants must take into consideration the desires, concerns and expectations of different parties that they must engage with throughout their caregiving role. Paige and Sarah had to learn how to “balance” all the roles that they had including not only being a caregiver, but also a mother, student, and formal personal support worker (profession). They also had to balance doing caregiving and spending time with the family member(s) that they were providing care for. The care recipients had full cognitive capacity, and there was a delicate balance between getting their loved ones to “do”, while trying to maintain their autonomy and agency. When trying to get her grandmother to do something, Paige was often met with “you can’t tell me what to do,” “I don’t have Alzheimer’s,” or a simple “no.” Both participants had to come up with different tactics including using different language when with speaking with their loved ones. Paige shared that she would tell her grandmother, “I’m not telling you what to do, I’m reminding you what works for you.” Another tactic utilised was to get someone else to convince them to do something, for example, Sarah shared: “I had to call

telehealth and speak to a nurse to convince him to have him go, to the hospital.” The caregivers also shared some of the frustrations when they are trying to get their loved ones to do something. Paige said that it was frustrating when she had to “deal with Mama (her grandmother) being in her right mind” and her belief that you’re telling her what to do. While, Sarah shared, “I would think it would have been easier if he was like, nonverbal. And then it was like, I can actually direct him.” The participants realized and had to accept that no matter how much they tried to convince their loved ones to do something that ultimately, if they did not want to do it, they could not be forced to.

The act of balancing also came into practice when the caregivers had to balance the wishes of their loved ones with the recommendations of health care professionals (HCPs). This was not only about getting their loved ones to do what the HCPs were recommending but also getting the HCPs to understand why their loved ones said “no”, instead of deeming them noncompliant. Not only does this work to maintain the autonomy of their loved ones, but it may also help to educate HCPs around acknowledging that some best practices may not always be efficacious with every patient. Moreover, HCPs may come to realize that some patients may benefit from alternative practices that better meet their needs, whilst ameliorating their own expectations as HCPs.

### ***Communication***

Communication was another subtheme that emerged and involved communicating with the family member(s) receiving care, other family members, friends and health care professionals. Paige and Sarah shared how they dealt with issues related to communicating with the family member to whom they are providing care to. They both had to talk to their loved ones about the impact of their words. Paige shared, “So now, it's in the moment being like, you know

what Mama that hurts like, you know, you can't say that, and this is why." Sarah said to her father, "You know, and I don't care if you are my father, I still don't deserve to be spoken to that way." Sometimes it did not work, and sometimes it did, with both participants seeing some changes in the ways in which their loved ones communicated. Paige shared, "Um, but truthfully, I've seen changes like, not big drastic, I'm a brand-new person changes, but like changes that make it more manageable." As Paige put it, "if you don't tell her, you don't give her the opportunity to try." This was especially important because the way in which her grandmother spoke to her was also the way in which she would sometimes speak to the PSWs, who were coming into her home to help her.

There were a few issues when caregivers had to communicate with other family members, including getting help, and passing on information to the rest of the family. Although asking for help from family members worked, generally help came episodically and on a temporary basis. Sometimes it was also difficult to communicate with other family members. Paige spoke about times when she felt bullied by other family members, who were also not helping in the caregiving. During these times, as the official caregiver, she carried veto power, and would exercise it. Others would try to bully her but she did not let the bullying work. Paige stated:

No, so she has like veto power pretty much where if they get into their get on their high horses, about foolishness, they know nothing about, Cora's (name changed to protect identity) like, Oh, you know what, that's not important right now. But what is important is this.

Communication among caregivers and other family members was improved by limiting the communication with the health care system and professionals to the primary caregivers, thus

pertinent information was passed on to the rest of the family in a consistent manner. Before this change, the family members involved in caregiving were not always being told of any changes to their loved one's care plans, including changes to their prescriptions.

Although ethnic background was not included in the demographic information collected from the participants, both participants spoke of the effects of cultural norms on caregiving.

Paige, who is Jamaican-Canadian, shared that there have been issues for the primary caregivers, herself and her cousin, who are grandchildren to their grandmother (the care recipient), sharing:

So just by nature, I think of culture, is that my aunts and my uncles think that they have more say, than us. The two happened to be her primary caregivers, which are her grandchildren. So it's balanced in the still being respectful and respect and tradition and all that kind of stuff with the no like, reasonably you guys are not making a good decision because you don't have all the information, you haven't been there you haven't seen.

Thus, because they are older and the children of the care recipient, they believe that they have a say in the care of their parent even though they are not providing care as well as not providing support to the primary caregivers. In addition, because they are the third generation, they were expected to listen and at times defer to older family members because they are considered their elders. Another issue that arose was dealing with her grandmother's expectation of her. Paige explained that because she was not working, her grandmother expected her to go over and help whenever her grandmother wanted her to. Her grandmother had this expectation even though Paige was the mother of a toddler and a student. Paige shared:

And then time, because I felt like my grandmother didn't understand, it became the same thing that made me flexibly enough to go and help with her caregiving was the same thing that was making it challenging for me to give her as much time because her mindset

is just if you're not in class, then you can be here, when it's like, no, when I'm not in class, I still have to do readings, I still have to do school work, I still have to rest my brain, I still have to clean my house, cook, you know, all that kind of stuff care for David. So, it's still a challenge getting her to understand that outside of caregiving for her, there's still a life that I need to attend to.

Sarah, who is Greek-Canadian, shared that in her Greek culture that it is the daughter who is responsible for the care of the aging parents, thus it fell on her and not her brother to provide care for their parent. Sarah shared:

I grew up in a, in a community or in a culture where you take care of family members. If I were to get married, and my parents were elderly, I would take them in if they couldn't live on their own. It's just part of culture. I think for for me being of the Greek background.

She also shared that her father doesn't listen to her because "I am his daughter and a woman". Living at home with her parents to whom she is providing care also made it difficult for her to be a caregiver for them, sharing:

They think that because I still live at home that they still think of me as a child that they have to take care of, ..., it's challenging to get them to understand that I don't need to be taken care of.

Sarah also stated:

I know, he's (Sarah's brother) got his things that he wants to do,... Um, my brother, he does help when he can, but he doesn't live with them, I live with my parents. He's married, no children. He works, he has a full-time job as well as nine to five. So,.. which was logical for me to change my schedule.

While saying that she wanted her brother to help, Sarah also seemed to excuse her brother from helping more.

Communicating with health care professionals could also be challenging, and it was especially challenging to get the HCPs to understand why the care recipient would not follow their recommendations. I think that it is also important to understand that there can be a difference between recommendations and following directions that cannot be compromised. For example, Paige shared her frustration with the dietician who was making dietary recommendations, stating:

She eats Jamaican food, ... trying to change her diet to a completely different cultural palette is, that doesn't make any sense to me, you don't think that it's within the scope of your job to figure out within what she already is accustomed to? To make a meal plan based on that? No, not your job?

It is also important to use different communications strategies to help ensure that the communications are consistent and shared with those involved in caregiving, other family members, as well as helping to ensure that the autonomy and agency of both the caregiver and care recipient are being maintained, including when interacting with the health care system.

To sustain themselves in their caregiving role, Paige and Sarah primarily relied on informal interventions and less so on formal interventions. Although Paige had a PSW helping her grandmother on a weekly basis, most of the caregiving was done by the informal caregivers, with additional help also coming from other family members who would step in when the caregivers needed temporary caregiver coverage. Sarah's parents refused to have outside help, as she shares in the following:



Yeah. So and trying to get outside help. They (parents) don't want it. I tried to get like, even something as somebody to come in to do the cleaning and do the laundry. They do not want strangers in the house.

Thus, Sarah was expected to do most of the caregiving tasks, except for the laborious outdoor tasks that her brother agreed to complete. This communication subtheme also included a recommendation from Sarah in how to support caregivers. Sarah shared:

I think the, I think there's a kind of, like a stigma, of people who look after their parents... Um, you and I think just maybe that, I think also the government needs to realize that, you know, the people who look after the parents are doing the government a favour.

Taking her experience about stigma further, Sarah recommended:

...And understand that, you know, like, if somebody has to look after the parents that there's no punishment for it. You know, there's no stigma for it. Because a lot of people have to leave their jobs to look after their parents.

Thus, Sarah suggested that one way of supporting informal caregivers was to combat the stigma associated with caregiving.

The caregivers in this study relied on informal interventions to sustain them in their caregiving role, while also relying on formal supports such as doctors, dieticians and PSWs. It should be noted that for this study there is a distinction between informal supports and informal interventions. One study referred to informal supports as being family, friends and neighbours who offer social supports (Shiba, Kondo, & Kondo, 2016). For this present study, informal interventions were interventions that are outside of the services and resources provided by professionals, such as health care professionals, and for these caregivers included sharing

caregiver responsibilities, self-care, and communication strategies. Informal interventions were also used when interacting with formal supports, for example, Paige changed her communication strategy when interacting with the dietician in order to highlight the need for the dietician to take into consideration her grandmother's cultural palette when making dietary recommendations.

## **Discussion**

When Paige and Sarah tried to get help from other family members, it seemed that asking them to take some responsibility in the care of their loved ones was more successful than asking for help, especially as caregiving became more intensive and moved from temporary to permanent. I suggest that when caregivers ask for help with caregiving from other family members that sometimes these other family members see it as helping the caregiver instead of the care recipient, which may make it easier for them to limit their help and/or to say no. When other family members take responsibility for certain caregiver tasks that need to be completed on an ongoing basis, it becomes their responsibility to make sure that it is done, whether it is by them personally or someone else on a permanent basis, or getting temporary coverage when needed.

The question then becomes why do the interventions that these young caregivers utilise primarily consist of informal interventions and less on formal interventions? Family dynamics and cultural norms were two of the intervening conditions that most affected the caregiver participants, the challenges associated with caregiving and the strategies used by the caregiver participants to sustain them in their caregiving role. Sharing caregiving responsibilities, asking for help and getting help resulted in the participants having to acknowledge and deal with the role that family dynamics plays in the care of their loved ones, which were affected by cultural norms. Sarah shared that she wanted her brother to help more in caring for their parents. As

Sarah wanted more help from him, it raises the following question: why is it okay for her to change her schedule and for her brother to help in a way that does not affect his ability to work and do other things? What about the things that she wants to do, when does she allow herself the time and space to do them?

Could the cultural norms and family dynamics affecting the experiences of these young caregivers reflect a collectivist construct, where the needs of others are valued above one's own personal needs, and are there important considerations related to this dynamic in relation to racialized and/or ethnic groups? Are there influences of familism, filial piety or communalism at work here? Among Hispanics, familism prioritises a person's relationship with their family, which includes honouring family and placing the needs of family members over one's own needs (Schwartz et al., 2010). For some African Americans, familism refers to the "the reliance on family for support, obligation towards members, and use of relatives as referents" (Rozario & DeRienzi, 2008, p. 772). Among many Asians, filial piety is grounded in the notion of reciprocity, where child-rearing is considered an investment that is then reciprocated by caring for their parents in old age, and can also include honouring one's family and placing their dreams and wishes above their own (Gui & Koropeczy-Cox, 2016; Schwartz et al., 2010). Among many Africans including those in North America, communalism places emphasis on social relationships and ties over the achievement of the individual. In addition, "these ties are to friends and family, which include nonblood kin, and are prioritised as an essential part of daily life" (Schwartz et al., 2010, p. 549).

We must be cautious when referring to these collectivist cultural contexts as the reason why caregivers become carers and why they may rely less on formal support and instead turn to informal supports. First, although more than adequate caregiver support initiative exists, there

are specific areas where the needs of all caregivers are not being met. This has resulted in inequitable and ineffective access to appropriate caregiver supports. For example, not all caregivers were aware of or planned to adopt caregiver education plans offered through the LHIN (Long-term Health Integrated Network). Also, not all supports are available throughout the province, especially in remote areas. Thus, the expectations and demands to provide care increases for these caregivers (Ontario Government, 2018). Second, instead of meeting the needs of the individual caregiver, I fear that because they are seen to be choosing to do their caregiving in a different way that they will not be given supports that assist them in the best way, thus leaving them to fend for themselves as they deal with the challenges associated with caregiving. Third, these collectivist cultural constructs focus on racialized groups, with the White or Eurocentric group held up as the standard to which all others are compared, leading to a few consequences. This Eurocentric group is excluded from being treated as a cultural group, and it assumes that they prioritise individualism, which ignores the diversity in cultural and ethnic groups that make up white and European groups (Schwartz et al., 2010). Caregivers who have become caregivers through a sense of ‘obligation’ as well as those who do caregiving differently, must also be supported in a way that best supports them in their caregiving roles, thus intervening conditions, including culture must be taken into consideration.

The findings of my study illustrate how the participants came to understand their role and themselves as caregivers. Limited to no supports and an increase in caregiving responsibilities and time required for caregiving led to the participants understanding that things would need to change for them to be caregivers for the long run. They divided caregiving tasks among those willing to help, which helped them in balancing their other roles and responsibilities. They practiced self-care, which included acknowledging that they were doing the best that they can,

and not feeling guilty when they were having a bad day and making time to spend with their loved one outside of providing care for them. Improved communication as well as changing communication strategies affected the way in which they communicated with family members and with health care professionals, which also helped to maintain not only their loved ones' agency, but theirs as well.

## **5: IMPLICATIONS AND CONCLUSION**

The importance of this research study is that it is the first step in examining the experiences of younger caregivers and allows us to take into consideration the challenges that they are dealing with and the recommendations that they suggest in order to better meet their needs. I believe that this study can be the first step in expanding our understanding of who caregivers are and interventions to help them in their caregiving role. Both caregivers in this study were the primary caregivers to their loved ones. While they did receive some help from other family members, most of the caregiving was being done by them. Caregiving is often done by one person, but why does it seem to fall onto one family member to become a caregiver? It may be important to have a primary caregiver who can accompany their loved one to regular doctor's appointments, or can act as their legal decision maker, but that should not exclude other family members from taking on some of the caregiver responsibilities. This would ease some of the burdens associated with caregiving by helping to ensure that majority of the caregiving does not fall to one person.

In addition, who we think a caregiver is also influences the type of interventions that are available since they were likely developed with these caregivers in mind. Caregiver interventions often arise out of research findings. However, if the caregivers who participate in these research studies are very homogenous, then this limits the efficacy of the caregiver interventions that arise from the research.. I believe that this limits what caregiver interventions can do and who they are going to help. Expanding the demographics of caregivers involved in these studies will allow us to better understand the needs of a more diverse group of caregivers. We must also consider that of those people who are now providing care to a family member or friend, how many of them consider themselves to be informal caregivers? How do we reach them? How can they come to

understand that they are caregivers? What would stop them from knowing or acknowledging that they are caregivers? These questions also need to be answered to get a better understanding of caregivers and their experiences.

We must also consider that becoming a caregiver is not always a choice over placing their loved ones in a LTCF, but rather a necessity. Placing a loved one in a LTCF can be very costly, with the cost of basic accommodations being \$1,891.31 per month (\$22,695.72 per year) (Ontario Government, 2019). In addition, there is a waitlist for LTC beds, averaging approximately a five year wait before they are able to gain access to a bed (Ontario Long Term Care Association, 2018). Therefore, even for family members who have decided to place their loved ones in a LTCF, family members will likely have to take on the caregiving responsibilities until an LTC bed becomes available for their loved one.

We must take into consideration factors that can influence caregiving, such as cultural norms. As social workers, knowing the effect of cultural norms on caregiving can better equip social workers to better support their caregiver clients, especially since cultural norms affect family dynamics including who, if anyone, should be responsible for aging parents. This could also help social workers communicate with HCPs to better meet the needs of the caregiver and their loved one, and for example, move the conversation from noncompliance to how to make it work for them. A recent study found that “one size does not fit all” when engaging in healthcare services. Rather, the context of the situation must be taken into consideration; flexibility should be incorporated around the caregiver’s circumstance; and the services should ‘fit’ the people (caregiver and cared person). This is especially important in that caregiving is dynamic and is affected by factors outside of caregiving, including financial situation, comorbidity, other responsibilities, family dynamics and culture (McPherson, Kayes, Moloczij, & Cummins, 2014).

I suggest that we move from focusing on formal caregiver services to including both formal and informal caregiver supports, which include interventions outside of traditional formal caregiver services.

Previous studies on the experiences of caregiving have generally included recommendations from the informal caregiver participants that focus on changes and recommendations for the health care system and how to support them, such as health care professional education and health care system navigators (Brémault-Phillips et al., 2016). Although there were a few recommendations from the caregivers in this study that were directed to the health care system and professionals, the caregivers focused on informal interventions to help sustain them as caregivers. Sarah suggested that one way of supporting informal caregivers was to combat the stigma associated with caregiving. Although Goffman (1963 cited Werner et al., 2012) defined stigma as an attribute that “reduces the bearer from a whole and usual person to a tainted discounted one” (p. 90), the concept of stigma has been refined to include self-stigma, public stigma and stigma by association. Self-stigma is the internalised experiences of those personally targeted by a stigma; public stigma refers to the reactions of others towards the stigmatised person or groups; and stigma by association affects those people surrounding the stigmatised person. The stigma by association includes family stigma, which consists of three dimensions: caregiver stigma, lay public stigma and structural stigma. Family stigma has been found to occur when there was a reduction in visits and interactions of others with the person living with Alzheimer’s and can occur with anyone living with a stigmatising illness (Werner et al., 2012). In addition, both the caregiver and their loved one experience a gradual shrinking of social networks and support systems (Werner et al., 2012).



In order to combat stigma, I believe that we must start by looking at the way in which we look at aging, disability and independence. Successful aging is associated with avoiding adverse conditions associated with aging, such as dementia. But this results in the exclusion of people who require caregiving because at least one of the three components in the concept of successful aging, low probability of disease and disease related disability, high cognitive and physical function, and active engagement (Rowe & Kahn, 1997), is compromised. Unfortunately, the concept of successful aging does little to accept the realities of life, decline and death. Instead successful aging avoids the processes of death and dying, thus ignoring factors beyond the individual that hinder their success. Aging must include adapting to and accepting changes and limitations that are not modifiable, and also include understanding and acceptance that dependence on others should not be feared, and instead be included as part of the cycle of life and living (Lamb, 2014).

Disability justice is an alternative way of thinking about disability and independence, which can also improve the lives of those living with complex health issues and, while not the focus, disability justice can also support their caregivers. Disability justice moves from disability rights, which focuses on accessibility, to challenging the thoughts around accessibility, along with fundamentally changing our understanding of organising and fighting for social change. Disability justice relates ableism to other forms of oppression, such as racism and sexism, and interrogates how the medical models of disability, health and wellness have been used to establish the notions of ableism and 'normal' (Mingus, 2011). Disability comes to be better understood as more complex, whole and interconnected, by highlighting the fact that all bodies are unique with both strengths that enable us to do and needs that must be met to be 'able' to do. (Mingus, 2011).

Disability justice can move society towards truly accepting our differences by removing the unearned privileges associated with able-bodied people as well as working to expose and remove the oppressions associated with those who are differently abled. By accepting differing abilities, differences become the norm, which can dismantle the universal subject, who also happens to be able-bodied. Disability justice may be able to support people by moving away from independence towards a society that acknowledges our interdependence, where social change moves towards a society where people are accepted where they are at, thus normalizing difference and the fact that we need help to be 'able' to do (Mingus, 2011). Whether we are born differently abled or become differently abled, this would go a long way to helping to combat the stigma associated with disabilities and complex health illness issues. While the focus would be those being stigmatised directly, caregivers could also benefit especially if they are experiencing stigma by association.

I also believe that simply being a caregiver can itself be stigmatising because of the value that we give to caregiving. Although there have been changes, we still live in a patriarchal society, where domestic labour and women are still relegated to the private sphere, thus affecting our social norms (Armstrong & Armstrong, 2010; Learner, 1986). As a result, domestic labour, which includes caregiving, is often undervalued, and there are several factors at play. First, it is unpaid work and thus has no purchasing power in our society. Secondly, although domestic labour does require training, because it is done in the home and the training itself is unpaid, this leads to domestic labour also being considered unskilled labour. In addition, domestic work is also considered to be unskilled because of the belief that women have the innate ability to do domestic work (Luxton & Corman, 2005). Thirdly, it is easier to acknowledge work that is seen, and since domestic work is unseen, it is made invisible work that remains unacknowledged and

is more likely to be undervalued (Armstrong & Armstrong, 2010). I believe that combating stigma would require changing the way we look at caregiving and the value placed on caregiving. I suggest that caregiving will continue to be unvalued until we acknowledge the actual value of caregiving, both financially as well as valuing its contribution to improving quality of life.

Sarah suggested that employers need to be more flexible and take into consideration the responsibilities of caregivers. Therefore, as Sarah suggests, where possible employers allow caregiver employees to partially work from home. This would also require a change in the value placed on caregiving, while also acknowledging the savings for the health care system and thus taxpayers through the unpaid work done by informal caregivers. Although the federal government has acknowledged that informal caregivers account for \$5 billion of unpaid work per year (Sawatzky & Fowler-Kerry, 2003), I would suggest that this estimate is on the lower side and does not take into account all of the caregiving done by informal caregivers, especially those who have never thought of themselves as caregivers.

We are familiar with the African proverb, “it takes a village to raise a child”, but there is a new saying, “It takes a village to care for a senior” (Kirk, 2017). Kirk (2017) suggests the “village” highlights the importance of family, friends and neighbours who are essential for promoting a healthy person. Taken further, I believe that this highlights the need to move caregiving out of the realm of the individual caregiver and into a more collectivist realm, where caregiving is a communal effort. This could, at the very least, support the caregivers but can lead us to not only better understand the caregiver experience, but to understanding the dynamic nature of caregiving. Understanding the dynamic nature of caregiving could then lead to

developing and implementing proactive interventions that also take into consideration what caregiving will look like in the future.

But will governments be willing to be proactive when it comes to supporting informal caregivers? This would likely increase the funding demands to support caregivers, and the savings would likely not be immediate or within a four-year political term. I believe that some of the interventions that are developed and implemented through government policy are reactive instead of proactive because being proactive often seems to cost more than being reactive, since a large portion of funding is required initially, and the results are not immediate. While being reactive may seem to cost less initially, it is often a band-aid or superficial solution to an ongoing issue and ends up costing us more in the long run. For example, the shortage of LTFC beds has resulted in older adults remaining in hospitals after they no longer need the services provided by the hospital because there are no spaces available to move them into LTCF and they are unable to return to their home. Thus, not only does it cost more to have them occupying hospital beds when they no longer require services, these hospital beds are then no longer available which adds to the hospital bed shortage and ‘hallway medicine’ (Wiercigroch & Weiyang, 2018). In addition, the government usually only focuses on the financial issue and looks for financial solutions, other factors, such as quality of life, are not prioritised.

### **Limitations of this Study**

One of the major limitations of this study was that because there were only two participants, it was unlikely that I reached a point where no new information emerged, thus saturation was also not achieved. Having more participants would allow for new information to emerge during coding and saturation to be achieved. A grounded theory approach works best when there are many participants, allowing for new information to emerge during coding until

saturation is achieved and there is not additional information found (Creswell & Poth, 2018; Oktay, Late-stage analysis, 2012c). The narrative approach, which tells the stories of individual experiences, can be used when there are one or more individuals (Creswell & Poth, 2018), makes it a better choice when the participant numbers are low.

One of the eligibility criteria was that younger caregivers must be caring for older adults aged 65 and older. By limiting the age of the care recipient to 65 and over, the potential caregiver participants were limited to an age range of approximately 45 and up, assuming they were caring for their parent(s). Future studies on the experiences of younger caregivers caring for older adults should not have a lower age limit for the care recipient in order to gain a better understanding of the experience of a more broadly diverse group of younger caregivers at various stages of their lives. This is especially important because the development and implementation of resources to support caregivers are often based on the caregiver studies, which are based on the needs and recommendations of the caregiver participants involved in those studies. Another limitation was the difficulty in finding younger caregiver participants, which in this case was achieved through networking and snowball recruitment. This may have occurred because younger caregiver may not see themselves as caregivers, as well as not be considered caregivers by others. Broadly speaking, the narrative of who is a caregiver should change in order to allow people who are providing caregiving to acknowledge themselves as caregivers and understand that they are able to access caregiver resources and supports.

### **Opportunities for Future Research**

Although not the focus of this study, the effect of cultural norms and ethnicity were intervening conditions that affected the experiences of the participants. Future research should delve deeper into these conditions, as well as other conditions, and their effect on caregiving in

general and the challenges they experienced and the interventions that they utilised. Doing so will help us gain more insight into how to better support caregivers, which is made up of a diverse group that include LGBTQ2+ folks, and racially, culturally, and ethnically diverse folks, thus strengthening the efficacy of the findings as they inform subsequent interventions. This is especially important because the lack of diversity of caregiver participants in research does not reflect the diversity of Canadians and specifically Canadians who are caregivers. We should also examine the existing barriers to accessing caregiver supports, the costs associated with being proactive and providing caregiver interventions that are flexible and context-led, and the costs of not supporting caregivers.

## **Conclusion**

The overall findings suggest that for these younger caregivers, dealing with challenges does not merely exist as an issue that strictly involves getting formal support, such as an increase in PSW hours or attending caregiver support groups. Rather, in order to continue being able to provide care to their loved ones, these caregivers dealt with the challenges associated with caregiving by primarily relying on informal interventions. For example, instead of increasing PSW hours, they asked other family members to help with the caregiving. But we must also take into consideration the reasons why they may not have gotten more formal types of supports. This includes having to take into consideration that their loved ones may not want strangers in their homes or doing personal care, the expectation that caregiving is the responsibility of the family, that those providing caregiving do not see themselves as caregivers, as well as not being given access or knowing about the formal caregiver supports that are available to them.

These findings highlight the need to continue examining informal caregiving and how to support informal caregivers. This is especially important since we are becoming more reliant on

informal caregivers to do more than provide a social connection to their loved ones. We cannot afford to not support caregivers because of the contributions they make to their loved ones in the form of care, and to society in the form of unpaid labour. If we do not support caregivers and they are unable to continue in their role as caregivers, their loved ones may be considered an additional ‘burden’ on the already strained healthcare system. While the finding of this study indicate that these younger caregivers deal with challenges using informal interventions, such as sharing caregiving responsibilities among other family members, we must be careful not to assume that they are not interacting with the HCS and when they do, that they are not experiencing challenges. Rather these findings simply highlight the challenges most affecting these caregivers and the ways in which they sustain themselves in their ever-changing caregiving role.

For some, becoming a caregiver is done because there is no other option, be it because of family obligation, finances, or inaccessibility to formal caregiving supports. For some, informal caregiving is more than just a family obligation and instead is simply the way things are done. Whatever the reason that has led to someone becoming a caregiver, caregivers should not be left to fend for themselves and their loved ones when the existing supports are not meeting their needs. One suggestion is to incorporate a context-led approach as well as flexibility that takes into consideration the circumstance of the caregiver and their loved one (McPherson et al., 2014), thus allowing supports to fit the needs of the individual instead of the individual having to try and fit into pre-prescribed supports that are unable to meet their specific needs. To better understand the experiences of caregivers requires that we expand our understanding of who may need caregiving, who is doing caregiving and what caregiving looks like. This study worked towards that by focusing on the experiences of younger caregivers, who had previously been

understudied, thus expanding our understanding of what, who and how it is done. Doing so will allow us to better support the diverse group of caregivers that continues to increasingly be relied upon.



## APPENDICES

### APPENDIX A

Recruitment email or phone call

Hello,

My name is Mathabo Mpela-Aren. I am a graduate student, researcher at Ryerson University in the School of Social Work. I am contacting you to see if you might be interested in participating in a research study. This research is being done as part of my master's project and my supervisor's name is Gordon Pon, Professor from the School of Social Work at Ryerson University.

The focus of the research is to explore the experiences of informal/family caregivers aged 55 or younger caring for older adults with complex health issues. To participate you need to be an informal/family caregiver aged 55 or younger, caring for an older adult, aged 65 or older with complex health issues. Participants must have been an informal/family caregiver for at least the previous six months. If you agree to volunteer, you will be asked to provide demographic information as well as participate in a one-on-one interview.

Participants will be asked to complete a one-time one-on-one interview. Interviews will be conducted in a place chosen by the participant, where privacy can be maintained, and other people cannot see or hear the interview. Interviews will be audio recorded, and notes will be taken. Participants will be asked open-ended questions and will be asked to share their experiences of caregiving. Participants will be asked to complete a demographic form at the end of the interview, which is expected to take approximately ten minutes to complete. Participants will have the option to 'opt-in' if they wish to review the transcripts of the interviews and make edits.

Your participation will involve one interview session that will be two to three hours.

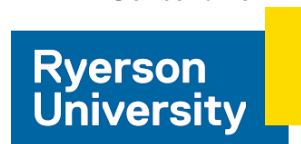
Potential and recruited participants identities will remain confidential throughout and after the study.

Your participation is completely voluntary and if you choose not to participate it will not impact your future relations with the investigator, Mathabo Mpela-Aren involved in the research, the supervisor Gordon Pon or Ryerson University. If you are interested in more information about the study or would like to volunteer, please reply to this email at [mmpelaaren@ryerson.ca](mailto:mmpelaaren@ryerson.ca) or call Supervisor: Gordon Pon, 416 979 5000 ext. 4786, [g2pon@ryerson.ca](mailto:g2pon@ryerson.ca).

This research has been reviewed by the Ryerson REB, the REB file number is (2019-020).

## APPENDIX B

### Consent Form



### **Ryerson University Consent Agreement**

You are being invited to participate in a research study. Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions to be sure you understand what your participation will involve.

#### TITLE OF THE STUDY

The experience of young caregivers of older adults who are living with complex health issues

#### INVESTIGATORS

This research study is being conducted by Mathabo Mpela-Aren and will be supervised by Gordon Pon from the School of Social Work at Ryerson University. If you have any questions or concerns about the research, please feel free to contact Mathabo Mpela-Aren, [mmpelaaren@ryerson.ca](mailto:mmpelaaren@ryerson.ca), Supervisor: Gordon Pon 416 979 5000 ext. 4786 [g2pon@ryerson.ca](mailto:g2pon@ryerson.ca)

#### PURPOSE OF THE STUDY

The purpose of the study is to explore the experiences of informal/family caregivers aged 55 or younger caring for older adults with complex health issues. Two to three caregivers will be recruited. Eligible participants will be caregivers, aged 55 or younger, caring for older adults, aged 65 or older, living with complex health issues. Participants must have been an informal/family caregiver for at least the previous six months. Potential participants will be considered ineligible if they are over the age of 55; have not been providing informal/family caregiving in for the six previous months; or the care recipient does not have complex health issues. This research is being conducted by a graduate student in partial completion of a degree requirement and will contribute to a major research paper.

#### WHAT YOU WILL BE ASKED TO DO

If you volunteer to participate in this study, you will be asked to do the following things:

- Participants will be asked to complete a one-time one-on-one interview.
  - The interview will be between two and three hours.
  - Interviews will be conducted in a place chosen by the participant, where privacy can be maintained, and other people cannot see or hear the interview.
  - Interviews will be audio recorded, and notes will be taken.
- Participants will be asked open-ended questions and will be asked to share their experiences of caregiving.
  - Sample questions: Tell me how you came to be a caregiver? What helps you manage in your caregiving role?

- Participants will be asked to complete a demographic form at the end of the interview, which is expected to take approximately ten minutes to complete.
  - Demographic data will include ages of participant and care recipient, gender, and their relation to the care recipient.
- Participants will have the option to ‘opt-in’ if they wish to review the transcripts of the interviews and make edits.
- At their discretion, participants can assess the final report at Ryerson’s digital repository (<https://digital.library.ryerson.ca/>), where it will be uploaded after completion.

### POTENTIAL BENEFITS

One of the benefits of this research project is that it provides the participant the opportunity to share and voice their experiences. This can benefit the participant by validating their experiences. Secondly, the information shared by the participant caregiver may contribute to ongoing research and discussion on this topic.

### WHAT ARE THE POTENTIAL RISKS TO YOU AS A PARTICIPANT?

As a result of participation in this study, participants may experience emotional discomfort while they are disclosing their caregiver experiences. Before the interview participants will be reminded that they can skip questions, take a break, or discontinue the interview permanently as well as withdraw from the study at any time. Participants will also be made aware of counselling and support resources they can access. After the interview, the researcher will check-in with the participant and offer them a counselling and support resource list. The researcher will also advise the participant that they can contact the researcher for information about accessing support services.

There is a low risk that personal identity will be revealed. To manage this risk, no personal information of identity will ever be included in the completed research publication. All demographic data will be stored securely in password protected files and destroyed in a timely manner. Pseudonyms will be used in the publication. Individuals will only be identified as “a caregiver”. This is a role that a significant number of people have.

### CONFIDENTIALITY

Potential and recruited participants identities will remain confidential throughout and after the study. Pseudonyms will be assigned to the participants. Mathabo Mpela-Aren, the primary researcher will have access to the research data. All data will only ever be kept by me, Mathabo Mpela-Aren, the single researcher.

Signed consent forms, audio recorded interviews, interview transcriptions, and contact information (names, email or phone number) will be collected. All digital data will be stored electronically under password protected files solely in the researcher’s computer. Signed consent forms and demographic information will be kept in a secure locker which is kept in a secure room only accessible to other Social Work graduate students.

The audio recordings will be password protected on the audio device and uploaded to password protected audio files. The audio-recordings will be deleted immediately after transcription and verification with participants. The transcriptions will be kept as password protected files up until the final draft of the paper is completed and submitted to the School of Social Work of Ryerson University – this is anticipated for mid-August 2019. The transcriptions are only kept until final

publication for the purpose of me being able to review them and write my paper. I, Mathabo Mpela-Aren, as the primary researcher, will have access to the raw and transcribed recordings. Once the paper is submitted to the School of Social Work of Ryerson University the transcriptions will be destroyed.

### COSTS OF PARTICIPATION

The anticipated costs directly related to participation is the time that participants participate in this research. There is no reimbursement for the participant's time. There may be transportation costs incurred by the participant and these costs will not be reimbursed.

### VOLUNTARY PARTICIPATION AND WITHDRAWAL

Participation in this study is completely voluntary. You can choose whether to be in this study or not. If any question makes you uncomfortable, you can skip that question. You may stop participating at any time. If you choose to stop participating, you may also choose to not have your data included in the study. Your choice of whether or not to participate will not influence your future relations with Ryerson University, Mathabo Mpela-Aren, the investigator involved in the research, or the supervisor Gordon Pon.

### ACKNOWLEDGMENTS

- 1) At their discretion, participants can assess the final report at Ryerson's digital repository, where it will be uploaded after completion. <https://digital.library.ryerson.ca/>
- 2) Participants will be contacted following the interview to review the transcript.

### QUESTIONS ABOUT THE STUDY

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact:

Mathabo Mpela-Aren, primary investigator  
Graduate Student in the School of Social Work  
Ryerson University  
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This study has been reviewed by the Ryerson University Research Ethics Board, the REB file number is (2019-020). If you have questions regarding your rights as a participant in this study, please contact:

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c/o Office of the Vice President, Research and Innovation  
Ryerson University  
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THE EXPERIENCE OF YOUNG CAREGIVERS OF OLDER ADULTS WITH COMPLEX  
HEALTH ISSUES

CONFIRMATION OF AGREEMENT

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to participate in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement. You have been told that by signing this consent agreement you are not giving up any of your legal rights.

\_\_\_\_\_  
Name of Participant (please print)

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

I agree to be audio-recorded for the purposes of this study. I understand how these recordings will be stored and destroyed.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

## APPENDIX C

### Interview Guide

Time of Interview:

Date:

Place:

Interviewer:

Interviewee:

Research Question: What are the experiences of young caregivers of older adults who are living with complex health issues?

The purpose of the study is to explore the experiences of informal/family caregivers aged 55 or younger caring for older adults who are living with complex health needs. Two to three caregivers will be recruited. Eligible participants will be caregivers, aged 55 or younger, of older adults, aged 65 or older, living with complex health issues. The aim of this interview is to get as much information on caregivers' perspectives as possible. There is no correct or incorrect answer, I want to hear about your experiences and what you think. This is a one-time one-on-one interview that will be between two and three hours. The interviews will be audio recorded and notes will be taken.

Remind participant that they can skip questions, take a break, or discontinue the interview permanently as well as withdraw from the study at any time.

Ask participant if they have any questions.

Ask participant to sign the consent form.

### Initial Open-Ended Questions

1. Tell me about how you came to be a caregiver?
2. What was going on in your life then?
3. How would you describe how you viewed caregiving before you became a caregiver?
  - a. How, if at all, has your view of caregiving changed?
4. How would you describe the person you were then?

### Intermediate Questions

1. Tell me about your thoughts and feelings when you realized that caregiving was a permanent part of your life?
2. What helps you manage in your caregiving role?
3. Who else is involved in caregiving?
  - a. When did they become involved?
  - b. How are they involved?
4. What are some of the challenges that you have experienced since becoming a caregiver?
  - a. Tell me the sources of these challenges?
5. What are some of the rewards that you have experienced since becoming a caregiver?

6. What helps you to manage in your caregiving role?
7. Who has been the most helpful to you during this time?
  - a. How have they been helpful?

#### Ending Questions

1. Tell me about the strengths that you discovered about yourself now?
2. What do you think are the most important ways that you sustain yourself as a caregiver?  
How did you discover, or create them?
3. What do you think are the most important ways to support you in your caregiving role?
4. Since becoming a caregiver, what advice would you give someone who has just discovered that they their caregiver role has become a permanent role in their life?
5. Is there anything that you might not have thought about before that occurred to you during this interview?

#### Coming to the end of the interview

- Check notes to see if further clarification is needed.
- Final Question: “Is there anything else that you would like to say?”
- Ask participant to fill out the demographic form.

#### Debrief, explain what happens after the interview

- Provide support and counselling resource list.
- Give the participants the option of ‘opting-in’ to review the transcripts of the interviews and make edits
  - Participants who choose to ‘opt-in’ will be contacted following the interview to review the transcript.
  - Remind the participant that the deadline for responding is 1 week after they have received the transcript, and if they do not respond it will be assumed that you are happy with the transcript as it stands.
- Remind the participant that their identity will remain confidential throughout and after the study.
- Remind participant that at their discretion, they can assess the final report at Ryerson’s digital repository (<https://digital.library.ryerson.ca/>), where it will be uploaded after completion.
- Remind participant that my contact information as well my supervisor’s and Ryerson University’s contact information is on the consent form.
- Thank the participant for their time and contribution.

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## APPENDIX D

### Data Collection Form – Demographic information

#### **Demographic information form**

Name	
Email Address	
Telephone number	
Age of caregiver	
Gender/Sex of Caregiver	
Relationship to care recipient(s)	
Age of care recipient	
Care recipient's complex health issue(s)	
Care recipient's ability level	
Length of care at study	
Living arrangement in relation to care recipient	
Formal care arrangement (PSW)	

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## APPENDIX E

### Counselling and Support Resource List

#### **Caregiver Support and Counselling**

##### **CANES Community Care**

10 Carlson Court, Suite 200, Etobicoke, ON., M9W 6L2

416-743-3892

[www.canes.on.ca](http://www.canes.on.ca)

- Service for older adults and/or the caregiver caring for the older adult

#### **Seniors and Caregivers Support**

##### **Family Service Toronto**

355 Church St, Toronto, ON., M5B 0B2

Service Access Unit: 416-595-9618

Office: 416-595-9230

[www.familyservicetoronto.org](http://www.familyservicetoronto.org)

- One-on-one counseling, group programs, support groups and practical assistance to help older adults 60 years and older, and those with disabilities 50 years and older, deal with abusive relationships, difficult medical conditions (such as Alzheimer Disease, stroke, depression), cope with change and loss, explore housing alternatives, access community support programs, or other issues

#### **Family and Caregiver Support - Scotiabank Learning Centre**

##### **Providence Healthcare**

3276 St Clair Ave E, Toronto, ON., M1L 1W1

416-285-3666 ext. 4177

[www.providence.on.ca](http://www.providence.on.ca)

- Resource centre for families learning to cope with life-altering illnesses such as diabetes, stroke, heart disease, dementia, arthritis and Parkinson's

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