The Saskatchewan Caregiver Experience Study: A Provincial Survey to Gather Perspectives and Set Priorities for Caregiver Support

A Thesis Submitted to the
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In the College of Nursing
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By
Steven Hall, RN

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Abstract

Introduction: Policies and services for older adults are increasingly focused on living in the community, rather than relying on institutions. In fact, a total of 70-80% of community care for older adults is provided by informal or family caregivers. With Canada’s aging population, the number of caregivers is growing. The purpose of the Saskatchewan Caregiver Experience Study was to map the experiences and perspectives of caregivers in Saskatchewan and to identify their priority support needs.

Method: An online qualitative survey was administered via SurveyMonkey and distributed via Facebook and community newsletters. The survey collected demographics and asked three open-ended questions regarding: (1) the challenges that caregivers experience; (2) the positive aspects of caregiving; (3) the support needs and priorities of Saskatchewan caregivers; as well as a fourth question where caregivers could freely express any other experiences or perspectives. Content analysis was the method used for data analysis.

Findings: N=355 caregivers responded to the survey. From the content analysis of each individual question, it was determined that the greatest challenges Saskatchewan caregivers experience are exhaustion, self-doubt, navigating complex systems, living their own lives, and caregiving at a distance. The main positive aspects identified by participants were related to the rewards of caregiving, having the ability and opportunity to care, ensuring quality care for the care recipient, and the experience of personal growth through being a caregiver. Lastly, support priorities of Saskatchewan caregivers were found to be help when they need it, an ear to listen and a shoulder to lean on, assistance in optimizing the care recipient’s health, having healthcare professionals that care, and improved policies, legislations, and regulations.

Conclusion: This study highlights the caregiver experience in Saskatchewan. Findings from the Saskatchewan Caregiver Experience Study can be used to create and implement support services and adapt policies to improve the experiences of the population of individuals caring for Saskatchewan’s aging population in the community.
Acknowledgments

There are many people who have supported me through the process of crafting this thesis that I have to thank. First of all, I owe so much thanks to my supervisor, Dr. Noelle Rohatinsky, and members of my committee, Dr. Shelley Peacock, and Dr. Lorraine Holtslander. The mentorship and guidance I received from the three of you has been invaluable to my learning and growth as a researcher. I would also like to thank Dr. Kristen Haase at the University of British Columbia for starting me on my journey in academia. You shared your passion for nursing research with me and I’ll carry it with me for the rest of my career.

Special shout-out to my second-year nursing instructor Cheryl Cummings, who has stayed with me over the years, encouraged me in advancing my nursing career, and has always been there for a cup of coffee and bout of support when I needed it. As well, I am so grateful for my fantastic coworkers on 6200 Medicine at Royal University Hospital for their continued interest in my research endeavours, but also for being the best, most supportive work family anyone could ever hope to have. I’m so lucky to be a part of the 6200 team and I wouldn’t be the nurse I am today without you guys – especially my wonderful work-wife and forever hero, Jeness Murrin.

I give my gratitude to the Saskatoon Council on Aging (specifically June and Leslie) for supporting my work on this thesis. I feel honoured that my research has been able to advance the support SCOA provides to older adults and their caregivers in our community and our province. Your constant encouragement has kept me truly dedicated to my work. I also send thanks to Janice, from the group Entr’elles, for translating this study into French, making it fully accessible to the Fransaskois community. I wish you a very happy retirement, Janice!

Thank you to my Mom and Dad, who live in Ottawa, Ontario. You supported me 8 years ago when I took a giant leap and moved to Saskatchewan, where I found my people and true home. You give me inspiration every day and, despite being on the other side of the country, I know you are never more than a phone call away when I need reassurance. Without a doubt, my dear son (dog) Max deserves a thanks, a treat, and perhaps a new toy for all of the snuggles and love he has given me when I have needed a break from writing.

Saving the most important for last, I owe the biggest thanks to Kris, my loving partner. You’re always by my side, cheering me on, putting up with my stress, and I could not have done this without your love and support.
Dedication

This work is dedicated to my mother, Karen Hall, who acted as a caregiver to both of my grandparents. Mom, you showed me your superpowers and I am so proud of you for all that you are. Love you forever and always.
Land Acknowledgement

I have called Saskatchewan home since 2015 and I am grateful to have had the opportunity to conduct this province-wide study, which spans Treaty territories 2, 4, 5, 6, 8, and 10, Homeland of the First Nations and Métis peoples.

Although the data collection process for this study was anonymous and ethnicity was not a collected demographic, a few participants wrote about their combined experience of being Indigenous and a caregiver to an older adult. One Indigenous participant (who reviewed this acknowledgement prior to its publication) reached out to me directly to share that she felt the survey tool did not allow her to express the inequalities she had experienced as an Indigenous caregiver. For this oversight, I am truly very sorry.

I am fortunate to live, work, and conduct research on this land and I recognize the importance of ensuring cultural safety and inclusivity among the Indigenous Peoples. I reflected on my communication with this participant in depth. It is clear to see that caregiving takes much strength – physically, emotionally, and spiritually. This participant took the time to personally share her experience as a caregiver with me. She shared stories with me about the strength she harnessed to be a caregiver. I realized from our conversation that, like anyone else, Indigenous persons deserve to have their stories of strength and resilience heard. But Indigenous people also deserve to have their voices heard as the First Peoples of this land on which I conduct research and, considering the histories of the land, they also deserve the right to identify as Indigenous while telling these stories to amplify and celebrate their strength and resilience.

From this reflection comes my commitment to ensuring that my future studies will allow for Indigenous people to raise their voices, fully express their experiences, and feel validated and valued in their participation. With all being said, from my heart, I would like to pay my respect to the First Nations and Métis peoples and ancestors of this beautiful place, as we continue to reaffirm our relationship with one another.
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CHAPTER 1: INTRODUCTION

Background

One-fifth of the overall population in Canada is 65 years of age or older (approximately 6.8 million Canadians) (Public Health Agency of Canada, 2020; Statistics Canada, 2020b). The increasing number of older adults is attributed to population growth worldwide and improved longevity (World Health Organization, 2014). Older adults typically have complex medical problems, higher rates of healthcare utilization, and require multiple service approaches (Grady, 2011; Vaingankar et al., 2016). It comes as no surprise that policies and services for older adults are increasingly focused on living in the community, rather than relying on institutions as the primary axis of care delivery, resulting in the sustainability of healthcare systems (Vanleerberghe et al., 2017). In fact, a total of 70-80% of community care for older adults is provided by informal or family caregivers, also known as carers (Carers Canada, 2021). There are 8.1 million Canadians that act as informal or family caregivers (Carers Canada, 2021). Moreover, caregivers contribute upwards of $25 billion CAD in unpaid labour to the Canadian health system (Hollander et al., 2009). With the aging population, the number of caregivers is growing. Carers Canada (2021) states on their website that the question is not ‘if you will become a caregiver,’ but rather ‘when will you become a caregiver?’ As the caregiver experience affects so many Canadians, it warrants considerable attention in research, practice, education, and policy. This chapter provides background on aspects of caregiving and provides the foundation for the thesis study that was undertaken to engage caregivers across Saskatchewan. Concepts related to caregiving are introduced throughout this chapter. Table 1.1 presents a collation of all definitions that are introduced in this chapter, in order of mention.

Defining Caregiving

Through the years, caregiving has been defined in different ways. Definitions of caregiving can be complex, moving beyond the act of caregiving and interpreting what emotions people associate with the act of caregiving (Solomon & George, 1996). Some have considered caregiving to be the “behavioural expression of [one’s] commitment to the well-being or protection of another person” (Pearlin et al., 1990, p. 583). The Canadian Institute for Health Information (2018) assigns a simplified definition to caregiving: “[caregivers are] individuals who take on an unpaid caring role to support someone with a diminishing physical ability, a debilitating cognitive condition, or a chronic life-limiting illness” (para. 2). The authors of a
concept analysis derived from nursing literature defined caregiving as the “provision by a family care provider of appropriate personal and health care for a family member or significant other” (Swanson et al., 1997, p. 68). However, the definition used in this study was crafted in a concept analysis that was comprehensive of nursing, sociology, and psychology perspectives:

“Caregiving is the process of helping another person who is unable to do for themselves in a ‘holistic’ (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotional skills, knowledge, time, and an emotional connection with the care recipient” (Hermanns & Mastel-Smith, 2012, p. 15).

**Types of Caregivers**

It is important to note that there are different types of caregivers and their level of involvement can be operationally defined by the number of caregiving tasks performed and the amount of time caregivers spend performing them (Schott-Baer, 1993). The ability to be involved is determined by many factors including the caregiver’s geographic distance from the care recipient (Horowitz & Boerner, 2017), prior commitments of the caregiver (Guberman et al., 1993), or the caregiver’s financial security and employment (Hollander et al., 2009). The motivation to be involved is described later in this chapter (see *Motivations for Caregiving*). The differences in caregiving that are attributed to gender are also described (see *Gender and Caregiving*). Ability, motivation, and gender are contributing factors to what type of caregiver one may become: a primary, secondary, or tertiary caregiver.

**Primary Caregivers**

Primary caregivers have the highest level of responsibility regarding care, perform the largest number of caregiving tasks, and invest the most time in their caregiving role (Dilworth-Anderson et al., 1999). They either provide care alone, or in conjunction with other types of caregivers (secondary and tertiary). Primary caregivers bear the full bore of caregiving duties, and while secondary and tertiary caregivers deserve attention, primary caregivers require the most support (Kucmanski et al., 2016). Sometimes, primary caregivers may experience frustration due to their high level of involvement and responsibility (Abendroth et al., 2014). Lack of nearby relatives, decreased frequency of interaction, and a history of conflict within the family (e.g. old sibling rivalries that resurface with the stress of increased responsibility) are detrimental to the perceived burden and general health status of primary caregivers (Crocco & Eisdorfer, 2014). The stress of the responsibility can result in broken connections and a sense of
isolation for caregivers. For example, when a spousal caregiver has adult children who cannot relate to the reality of their one parent’s declining health (Abendroth et al., 2014). A participant in a study by Abendroth et al. (2014) stated: “Nobody sees my husband’s full condition… The children don’t see it. Somebody just needs to stay with him a week or maybe 24 hours. I think they’d be shocked that he’s lost so much of his abilities” (p. 52). For individuals new to the caregiving role, experienced caregivers have recommended identifying secondary caregivers early on, in preparation for when primary caregivers reach the point of requiring respite (Angelo et al., 2013).

**Secondary Caregivers**

Secondary caregivers perform tasks at a similar level to that of the primary caregiver, but without the same level of responsibility (Dilworth-Anderson et al., 1999). They are not typically in charge of making decisions about the care recipient’s support and care, and only provide care in conjunction with primary caregivers (Dilworth-Anderson et al., 1999). Secondary caregivers may live farther away from the care recipient, which is why they take on a secondary role in long-distance caregiving (Cagle & Munn, 2012). However, between one-third and one-half of long-distance caregivers still act in a primary role, contrary to what may be assumed given the distance between them and the care recipient (Koerin & Harrigan, 2003). The role of the secondary caregiver can be instrumental in maintaining the well-being of the care recipient and the primary caregiver. For the primary caregiver, occasional respite can be provided in ways such as assisting with overnight care or taking the care recipient for outings (Gaugler et al., 2003). For the care recipient, the influence of secondary caregivers has been shown to have positive impacts on older adults’ willingness to participate in social activities and programs (M. N. Aung et al., 2021; T. N. N. Aung et al., 2021; Zheng & Yang, 2019).

**Tertiary Caregivers**

Tertiary caregivers have little to no responsibility for making decisions regarding the care recipient and solely provide assistance with instrumental activities of daily living such as grocery shopping, yard work, or providing meals (Dilworth-Anderson et al., 1999). Tertiary caregivers may also replace the primary caregiver for short periods (Kucmanski et al., 2016).

**Defining Care Recipient**

Despite extensive searching of scholarly databases and grey literature, a conceptual definition of care recipient was unable to be retrieved. However, the most straightforward
definition of care recipient is *one who receives care*. Care recipient attributes may include physical disability, cognitive impairment, and behaviour challenges, all which have impact upon the physical and emotional health of their caregivers (Pinquart & Sörensen, 2007).

Caring *about* an individual involves a psychological connection and the expression of affection and love (Hooyman & Gonyea, 1995). Caring *for* an individual involves carrying out tasks such as personal assistance, paying bills, and transportation (Hooyman & Gonyea, 1995). Although it is prevalent within literature to use the term “loved one” synonymously with care recipient, some researchers may see this statement as controversial. For example, the caregiver experience can sometimes be invisible due to the fusion of ‘caring about’ and ‘caring for’ (Hooyman & Gonyea, 1995). Caregivers may also feel an obligation to care for, but not care about, highlighting the absence of love in a caregiving relationship, as sometimes, love is not the motivating factor. Guberman et al. (1993) refer to this as the “dark side of blood ties” (p. 190) and connect it to feelings of duty and obligation. Therefore, how can one truly assume that love is part of the caregiving exchange? For this reason, the term “loved one” will not be used within this thesis.

**Reasons for Caregiving**

Reasons and motivations are distinctly described within this thesis, where *reasons* describe the factors that make caregiving a necessary task, and *motivations* are the factors that lead an individual to choose to be a caregiver. There are many reasons that constitute the need for caregiving. The three reasons prevalent within the literature are chronic diseases and chronic illness; dementia and related syndromes; and palliation and end of life.

*Chronic Diseases and Chronic Illness*

Chronic diseases are of long duration and slow progression (World Health Organization, 2014). The four main types are cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes (World Health Organization, 2014). Chronic diseases can significantly impair quality of life, put individuals at risk for secondary complications and further disability (Shewchuk & Elliott, 2000). The diagnosis of a chronic disease forces a person to attend to the illness. While chronic disease is a medical term, chronic illness is defined as the subjective experience of loss of health due to chronic disease, which may also encompass mental illnesses that may accompany chronic disease (Paterson, 2001). Some caregivers or care recipients may choose an illness-in-the-foreground perspective, where the focus is placed on the sickness,
suffering, loss, and burden associated with living with a chronic disease (Paterson, 2001). Others may select a wellness-in-the-foreground perspective, where the person creates a dissonance between self-identity and the identity that is shaped by the disease (Fife, 1994; Paterson, 2001). Aside from the perspectives of the person living with chronic illness, chronic diseases are a prevalent reason for needing the support of family or informal caregivers, due to the limited availability of formal services (Shewchuk & Elliott, 2000). Moreover, the perspective which the care recipient chooses affects their health and well-being which, in turn, affects the health and well-being of the caregiver.

**Dementia and Related Syndromes**

Dementia is an umbrella term that encompasses a group of symptoms such as difficulties with memory, language, problem-solving, and other thinking skills that affect a person’s ability to perform activities of daily living (Alzheimer’s Association, 2020). Dementia has many causes, such as Alzheimer’s disease, vascular dementia, Lewy body dementia, and frontotemporal dementia, with Alzheimer’s disease being the most common (Alzheimer’s Association, 2020). Additionally, older adults with dementia have a higher prevalence of multiple chronic conditions (MCCs) (Koroukian et al., 2017). In cases of care recipients living with both dementia and chronic illness, complexities of the MCCs contribute to added debilitation and create greater challenges than caregiving for an individual with a single condition (Peacock et al., 2020). Caregiver burden is prevalent in a large population of caregivers to persons with dementia (Connors et al., 2020). A longitudinal study of 781 Australian caregivers to persons with dementia showed that 56.8% of caregivers had clinically significant levels of burden at the three-year timepoint (Connors et al., 2020). In Canada, two-thirds of caregivers find the experience of caring for someone with dementia to be socially isolating (Alzheimer Society of Canada, 2018). Moreover, 87% of caregivers wish that more people understood the realities of caring for someone with dementia (Alzheimer Society of Canada, 2018).

**Palliation and End of Life**

The end of a person’s life is an experience with many complexities, such as changes in roles and relationships, feelings of loss and insecurity, manifestations of illness, and potential threats to income and financial security (Duggleby et al., 2017). Caregivers have described providing palliative and end of life care as challenging, exhausting, and difficult (Holtslander et al., 2005). Concerns expressed by caregivers include uncertainty of what to do in times of a care
recipient’s symptom distress and the significant personal cost involved (Holtslander et al., 2005). Severe grief symptoms in advance of the care recipient’s death, also known as anticipatory grief, are associated with complicated grief and depression after the loss (Nielsen et al., 2017). These grief symptoms in the pre-loss phase are significantly associated with distress, low preparedness, and little communication during caregiving (Nielsen et al., 2017). These challenges highlight the need to implement and improve services and interventions to support family caregivers during this period of time.

**Motivations for Caregiving**

Caregivers may be motivated by a variety of factors to provide support. Motivators include intrinsic factors, reciprocity, commitment, and behaviour modeling (Brémault-Phillips et al., 2016). Some are motivated to provide support out of love, such as in cases of adult children who want to repay their parent’s love and dedication from their upbringing (Brémault-Phillips et al., 2016). These actions might also be behaviour modeling for the caregivers’ own children, teaching compassion and demonstrating personal growth (Brémault-Phillips et al., 2016). Spouses may provide care out of enduring commitment to their partner (Killner & Soundy, 2018) and they are also arguably the most affected by the responsibility of giving care (Killner & Soundy, 2018; Pakenham & Samios, 2013).

In their book *Et si l’amour ne suffisait pas* [*And if love was not enough*], French Canadian authors Guberman et al. (1993) provide a collation of motivations for caregiving from a Canadian perspective. The motivating factors for caregiving they describe are listed in Table 1.2, each with a brief summary of what is in detail within the book. Although dated, this publication provides a historical perspective of contributing factors to the motivation for caregiving, or what the authors refer to as ‘*la prise en charge*’ [the task at hand] (Guberman et al., 1993), all of which still hold true in today’s society.

**Health Impacts of Caregiving**

Caregiving is physically and emotionally demanding. The demands of the caregiving role often result in caregiver exhaustion, social isolation, economic hardship, family conflict, and conflict in the workplace (Coe & Neufeld, 1999). Caregivers are often required to perform a variety of tasks that differ in terms of the level of intensity. For example, the prevalence of musculoskeletal discomfort from the physical demand of informal caregiving has been identified (Darragh et al., 2015), such as when having to assist a care recipient who has fallen (Vaughon et
Emotionally, caregiving can be exhausting, as many individuals report not focusing on their own needs, but rather exerting all energy into the care recipient’s interests and feelings (Hermanns & Mastel-Smith, 2012). Some caregivers also face their own health challenges and these individuals are required to harness strength to care for another person while also managing their own care (Haase, Hall, et al., 2021).

**Employment and Finances**

In Canada, almost half of all caregivers (47%) provide care to their parents or parents-in-law and this is additionally common among caregivers aged 45 to 64 (61%) (Statistics Canada, 2020a). Moreover, half of all caregivers are also within the age range of 45 to 65, which are considered prime earning years (Carers Canada, 2021). These caregivers are often juggling their paid work and caregiving responsibilities, with varying levels of workplace support. This juggling of roles is interestingly notable between urban and rural settings, where rural caregivers report having access to fewer workplace supportive programs such as paid leave, employee assistance, and the opportunity to telecommunicate or work from home (Henning-Smith & Lahr, 2019). Time invested in caregiving can also be exorbitant. A study of caregivers to persons with Alzheimer's disease reported that caregivers were spending an average of 65 hours (range 8-168) in a typical week providing care (DiBenedetti et al., 2020). Many caregivers also carry the financial burden of costs associated with medical services, supplies, medications, and transportation – often using their own income and savings to manage costs (Charles et al., 2017). It is not uncommon for Canadians to be forced to choose between maintaining their paid employment and acting as an informal caregiver (Carstairs & Keon, 2009; Peacock et al., 2020). These choices can result in financial strain due to caregiving duties and financial demands (Lee & Zurlo, 2014).

**Gender and Caregiving**

Caregiving has rested heavily on women within the context of family, as women are believed to have a natural aptitude for caring (Peacock et al., 2020). In Canada, roughly 54% of caregivers are women (Sinha, 2013). Furthermore, women bear caregiving work that is more likely to be higher intensity than that of their male counterparts (Carstairs & Keon, 2009). A personal toll in the form of increased stress and other health issues may be worse for women than men (Perkins et al., 2013; Polenick et al., 2017; Swinkels et al., 2019). Many caregivers place
self-care as secondary to the care of the care recipient, and the risk for self-care deficit is heightened when caring for an ailing spouse (Polenick et al., 2017).

Societal norms and pressures see women as the expected caregivers (Hooyman & Gonyea, 1995; Wuest, 2001). As such, women end up contributing more hours to their caregiving role and assisting with more hands-on care, such as activities of daily living, housework, and meal preparation (Willert & Minnotte, 2021). In addition, women are more likely to have poorer mental health outcomes due to caregiving (Polenick et al., 2017; Willert & Minnotte, 2021). Women as caregivers, as well as the value of their role, have been historically invisible in public policy (Hooyman & Gonyea, 1995; Huang et al., 2021; Joseph & Joseph, 2019). Wuest’s (2001) Feminist Theory of Women’s Caring argues that the basic problem for women caregivers is the changing and competing caring demands (Wuest, 2001). Wuest’s framework has previously been applied to understand the experiences of women caregivers to older adults with dementia and multiple chronic diseases (Peacock et al., 2020). Findings showed that participants had to draw on intrinsic strength to develop strategies to navigate fraying connections and maximize resources.

Men tend to have a task-oriented approach to their caregiving role, seeing it as a challenge and focusing on specific tasks needed for caring (Swinkels et al., 2019). As such, support service use differs between men and women caregivers. Women caregivers tend to benefit more from counseling and educational services (Chen, 2014), which may be due to the well-ascertained fact that female caregivers experience higher levels of stress, burden, and strain (Kramer & Kipnis, 1995; Lawrence et al., 2002; Wallsten, 2000). However, previous findings have indicated men caregivers report more financial strain (Lee & Zurlo, 2014; Willert & Minnotte, 2021). While men caregivers do not benefit as much from counseling and psychoeducation, they do benefit from respite and supplemental services, such as meal delivery services and homecare nursing (Chen, 2014). Men caregivers who access community services have lower subjective burden and higher caregiver satisfaction (Chen, 2014).

**Caregiver Burden**

Caregiver burden has been described as the caregiver’s emotional evaluation of the caregiving exchange, expressed as the extent to which the caregiver finds it challenging to care for the recipient (Montgomery & Borgatta, 1989). Caregiver stress is the feeling experienced by caregivers when they perceive the demands of caregiving have exceeded the personal and social
resources of which they are able to mobilize (Lazarus & Folkman, 1984). Spousal caregivers are at the highest risk of caregiver burden, compared to other informal caregivers (Pearlin et al., 1990; Pinquart & Sörensen, 2007). Furthermore, caregiver burden is both objective and subjective. Objective burden is the extent of disruptions in the caregiver’s life, whereas subjective burden reflects the caregiver’s stress and nervousness related to their role (Montgomery & Borgatta, 1989). Different factors contribute to both objective and subjective burden. For example, in the case of individuals living with dementia, subjective burden in the caregiver has been found to be most affected by the care recipient’s memory and behaviour (Van der Lee et al., 2014). Support helps to alleviate caregiver burden and can be either instrumental (assistance in caregiving) or emotional (understanding and comforting) (Swinkels et al., 2019).

**Caregiver Satisfaction**

Despite the burdensome aspects of caregiving, many caregivers find satisfaction in their role. Lawton et al. (1989) defined caregiver satisfaction as a major dimension of caregiving that represents subjectively perceived gains from desirable aspects of caregiving. Satisfaction is viewed as having two aspects: appraisal and outcome (Son et al., 2000). Satisfaction can be measured through the caregiver’s positive appraisal of the caregiving role (Kramer, 1997a). While a caregiver’s appraisal of distress leads to burden, the appraisal of positive role gains allows for caregivers to recognize their satisfaction in the caregiver experience (Kramer, 1997a). Kramer (1997a) referred to this process as the “appraisal of strain and gain” (p. 240), where gain is the extent to which the caregiving role is appraised to enhance an individual’s life and be enriching. Satisfaction can also be an outcome variable, with three primary meanings: a sense of satisfaction in the role, feeling closer to the care recipient, and a sense of reward (Son et al., 2000). Positive emotional responses to caregiving involve a sense of fulfilment in caring for their care recipient (Hermanns & Mastel-Smith, 2012). Sacco and Copel (2018) cite feelings of accomplishment, inspiration, enrichment, and invigoration in their concept analysis of compassion satisfaction. Therefore, it is highly important to note that there are positive aspects to the caregiver experience that result in role satisfaction.

**Coping While Caring**

Social support has long been shown to enhance the health status of caregivers, by preventing stress, enhancing coping ability, promoting healthy behaviours, self-care, and health service use (Coe & Neufeld, 1999). Pre-existing health status can have an impact on a
caregiver’s ability to cope. It has been previously described that persons in good physical health are more likely to become caregivers, as well as continue being caregivers (McCann et al., 2004). There is a significant amount of inner strength one must draw on while providing support in their caregiving role (Brémault-Phillips et al., 2016). Some caregivers may find this strength through spirituality and their connection to faith. In a study conducted by Brémault-Phillips et al. (2016), the strength of the human spirit was described in cases where caregivers whose relationship with their care partners was complicated by past estrangement or abuse. These individuals harnessed their spirituality, which enabled them to forgive and heal. For caregiver-care recipient dyads who are facing serious illness, engaging in the process of reflection on the meaning of life and on the major spiritual and existential questions of life can assist with the processing and acknowledgement of the illness and its consequences and allow for enhanced coping (Molzahn et al., 2012).

**Bereavement After Caregiving**

The needs of bereaved caregivers have been mostly neglected in the delivery of palliative care services. Although bereavement services are integral to palliative care (Holtslander, 2008), a scarcity of resources, lack of time, and too few qualified personnel exist as barriers to supporting bereaved caregivers (Naef et al., 2020). Bereavement is “a state of loss, triggering a grief reaction that manifests in a set of behaviours known as mourning” (Buglass, 2010, p. 44). The psychosocial context of bereavement is multi-leveled. Holtslander and Duggleby (2010) identify three specific contexts in a study with bereaved older women: intrapersonal, interpersonal, and community/societal context. The intrapersonal facet is described as “losing a part of yourself” (p. 114), where bereaved caregivers experience the pain and loneliness of losing a life partner, while dealing with the memories and exhaustion that follow caregiving duties. Interpersonal context encompasses bereaved caregivers adjusting to life, or “striking out” (p. 116) on their own, while still needing the support of others. Lastly, community/societal context involves newly widowed individuals finding their way after a loss of identity in their social world, having to foster a “new me” (p. 117).

**Spirituality and Hope**

Spirituality and hope are cited in several studies as providing guidance, strength, and comfort to caregivers (Duggleby et al., 2021). The Theory of the Process of Hope (Holtslander et al., 2005) examines the experience of hope for informal caregivers of palliative patients.
Holtslander et al. (2005) define hope as “inner strength that [gives caregivers] the courage and ability to go through a difficult situation” (p. 289). An inverse relationship exists between caregivers’ hope and caregiver burden, where hope is a negatively associated with burden (Duggleby et al., 2021). Hope, as a concept and experience, may differ for older adults than for younger adults (Duggleby et al., 2012). Therefore, strategies must be established to foster hope with older adults living with chronic illness. Finding meaning and purpose, as well as transcendence of suffering can be aided by strategies such as adjustment to transitions and losses, life review, reminiscence therapy, and spiritual support (Duggleby et al., 2012). Furthermore, hope is a significant factor in all aspects of quality of life, which highlights the importance of hope for informal and family caregivers (Duggleby et al., 2011).

**Quality of Life**

Quality of life (QOL) is a significant attribute to be examined for both caregivers and care recipients. QOL is also a major factor in the ability or inability to age in place (Vanleerberghe et al., 2017). Older adults have indicated that their own home and community are positive impacts on QOL (Bowling et al., 2003). Therefore, QOL and aging in place truly come together as a pair. There are two facets that warrant description in relation to caregiving – QOL and health-related quality of life (HRQL), both of which have been defined uniquely within the literature (Vanleerberghe et al., 2017). With that being said, some scholars argue that HRQL overlaps with QOL, causing confusion (Karimi & Brazier, 2016). Despite this debate, two definitions, derived from concept analyses, are consistently cited within the literature. Felce and Perry (1995) described QOL in their concept analysis as an elusive concept that can come from an assessment of societal or community wellbeing, to the specific evaluation of situations of individuals or groups. They noted that operational definitions of QOL are diverse and vary by the range of applicable theoretical models (Felce & Perry, 1995). Ultimately, the definition derived from their concept analysis was that QOL is “an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values” (Felce & Perry, 1995, p. 60). A requisite caregiving character trait cited by Hermanns & Mastel-Smith (2012) was grounded in the goal of improved QOL: “the desire to make a difference, alleviate pain and suffering, and make things better” (p. 11). While the QOL of the care recipient is relevant, it is not the only concern in the caregiving exchange. Caregivers
are at a high risk for diminished QOL due to the time and energy involved in providing the required care (Glozman, 2004), relating back to the burden of caregiving and its contributing factors. Therefore, QOL is a relevant aspect to examine in both caregivers and care recipients.

**Health-Related Quality of Life**

Ebrahim (1995) examined HRQL from a public health perspective, describing the burden and consequences of disease. HRQL had been previously described as the value assigned to duration of life, as modified by the cognitive and functional states and social opportunities that are influenced by disease, treatment, or policy (Erickson & Patrick, 1993). However, Ebrahim provided a narrowed definition, stating HRQL is the “aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment” (Ebrahim, 1995, p. 1384).

Caregivers’ health and HRQL have been shown to be affected negatively by their caregiving duties (Yang et al., 2012). Their role poses inordinate psychological and physical challenges that leads to strain and emotional expenditure (Yang et al., 2012). Caregivers rely on social networks to receive support in their caregiving role and to maintain their emotional and physical health (De Maria et al., 2020). It has been found that caregivers to individuals with multiple chronic conditions require more social support than those with a single chronic disease, due to an additive effect of the stressors and self-management requirements for each disease (Bugajski et al., 2019). However, the social engagements of caregivers can be hindered by their caregiving role, thus affecting their HRQL.

**Aging in Place**

The caregiver’s QOL and ability to cope plays a large role in an older adult’s ability to age in place. Aging in place in Canada is defined as caregivers and care recipients having the health and social supports available to assist care recipients in living safely in their home for as long as they are able (Government of Canada, 2012). The World Health Organization (2004) states that aging in place involves the provision of appropriate services and assistance to meet the desire and ability of people in their current homes to prevent or delay moves to dependent facilities, such as nursing homes. Research has shown that older adults in western countries prefer to live in their own familiar environment for as long as possible (Gilleard et al., 2007; Gonyea & Burnes, 2013; Schosserer et al., 2015). A sense of belonging or attachment to place can maintain a sense of identity and well-being, and facilitates successful adjustments that are required throughout the aging process (Wiles et al., 2009). However, the progressive and
functional decline some older adults may experience causes them to be increasingly dependent on support and remarkably more susceptible to admission into long term care (Eaker et al., 2002). Most older adults prefer to age in place because it allows them to maintain independence and autonomy and reduces social isolation and loneliness (Schorr & Khalaila, 2018). Changing policies and practice allow for more possibilities for older adults to stay in their homes and communities; however, this shifts the responsibility of care onto families and informal caregivers (Wiles, 2003). Despite changing policies and the creation of initiatives such as tax benefits (Carstairs & Keon, 2009), Canadian caregivers spent $12.6 million out-of-pocket in 2013 for expenses related to their caregiving role (Fast, Keating, et al., 2013), highlighting the need for increased caregiver support services within the community.

**Caregiver Support Services and Needs**

Support needs are diversely prioritized in different geographical and contextual settings, which will be further iterated in Chapter 2. For example, the prioritized needs of caregivers to older adults living with dementia may differ from those of caregivers to older adults with cancer. Moreover, the prioritized needs of caregivers in the United Kingdom differ from those of caregivers in Australia or the United States. Services to support caregivers continue to grow and categories include respite care, psychoeducation, and support groups. These service categories are described herein.

**Respite Care**

Respite is a temporary period of rest provided at different intervals. Hanson et al. (1999) seminally described respite care as both a service and an outcome. As a service, they iterated that respite covers a spectrum of possibilities ranging from home care services, to adult day care, to short-term stays in long term care facilities (Hanson et al., 1999). As an outcome, respite is seen to provide relief for the family carer (Hanson et al., 1999). Receiving respite care is a vital and often unmet need of caregivers (Atoyebi et al., 2022; Bressan et al., 2020). A systematic review by Maffioletti et al. (2019) examined the effectiveness of adult daycare respite programs and retrieved no randomized control trials in their search. Nonetheless, they were able to determine that respite was effective at improving caregiver outcomes (Maffioletti et al., 2019). These outcomes included reduced feelings of burden, worry, anger, depression, and loneliness; increased feelings of competence, freedom, strengthened coping strategies; improved health status; and overall enhanced psychological well-being (Maffioletti et al., 2019).
**Psychoeducation**

Psychoeducation provides caregivers with information on how to manage aspects of their role, which includes exploring the caregiver’s self-care needs, family relationships, and future expectations for caregiving (Moss et al., 2019). Psychoeducation is systematic and structured, and serves to transfer didactic knowledge for an illness and its treatment, as well as to enable caregivers and care recipients to cope with said illnesses (Ekhtiari et al., 2017). Psychoeducational interventions, as well as therapeutic counselling, are specific approaches that assist with reducing anxiety and burden and improving caregiver QOL (Moss et al., 2019). Hooyman and Gonyea (1995) list five outcomes of psychoeducation, stating it can: (a) address cognitive and behavioural issues, thereby increasing caregiver knowledge; (b) teach coping strategies; (c) improve caregiver knowledge about resources and care alternatives; (d) produce feelings of being connected to and supported by others; and I provide methods to address secondary strains in other areas of the lives of caregivers.

**Support Groups**

Support groups for caregivers can strengthen the caregiver’s motivation to continue providing care and compensate for their decreased social involvement (Moss et al., 2019). Furthermore, support groups provide opportunities for caregivers to express their negative feelings and receive validation from others in similar situations. The sessions can be facilitated in person but are increasingly being delivered in online formats (Ploeg et al., 2017; Ploeg et al., 2018). Caregiving downtime, i.e. having time to participate in a support group, is identified as a contextual factor to influence support group engagement (Washington et al., 2020). Factors that negatively influence support group engagement include a perceived lack of need for support, reluctance to share personal information, and time-consuming caregiving commitments (Washington et al., 2020). Since social support is ascertained to be preventative for caregiver burden and stress (Coe & Neufeld, 1999; De Maria et al., 2020; Swinkels et al., 2019), support groups are a critical intervention to ensuring the wellness of caregivers.

**Problem Statement**

Saskatchewan is one of Canada’s 10 provinces and one of the three prairie provinces. The population is distributed throughout the province in a mix of urban and rural settings. It is reported that almost 16% of Saskatchewan’s population are older adults over the age of 65 (Government of Saskatchewan, 2017). Caregivers play a significant role in the lives of older
adults in Saskatchewan and pressures for informal caregivers increase with the aging population. However, there have been few efforts to identify the experiences of Saskatchewan caregivers and to involve caregivers in setting priorities for support services they access. One quality improvement initiative (Hall & Holtslander, 2022) was conducted in Saskatoon, Saskatchewan by the student (SH) prior to this study, which is described in Chapter 3. The data from this initiative was used in a grant application to PetroCan CareMaker’s Foundation. Subsequently, a grant of $110,000 CAD was awarded to the Saskatoon Council on Aging (SCOA) to expand caregiver support programming in the province through the creation of the Saskatchewan Caregiver Information and Support Centre (SCISC). Since Saskatchewan’s population is diversely distributed in geography, and it has been previously ascertained that the needs of older adults differ between urban and rural settings (Dal Bello-Haas et al., 2014; Saskatchewan Seniors Mechanism Research & Issues Committee, 2019), it was important to conduct an expanded project that sought to understand the experiences and perspectives of Saskatchewan residents in all settings. Therefore, the purpose of this study was to describe the experiences and perspectives of caregivers in Saskatchewan and to identify the priority support needs of these caregivers.

**Research Questions and Objectives**

The research questions for the study were: (1) What are the challenges and positive aspects of the caregiver experience in Saskatchewan? (2) What do caregivers to older adults in Saskatchewan identify as priorities for support? The objectives were to: (1) Explore informal caregiver experiences in both large urban and small centre or rural areas of Saskatchewan; and (2) Identify caregivers’ priority support needs to facilitate their caregiving role.

**Relevance of the Study**

New and experienced caregivers alike may experience difficulty accessing assistance, community resources, support, and adequate finances (Garcia-Ptacek et al., 2019). Therefore, the necessity of developing accessible and acceptable services that address the range of needs is critical to assisting this population (Harrop et al., 2014). There is also a need for a Saskatchewan context within the Canadian literature, which will highlight the needs and priorities of individuals in a province blended in urban and rural settings. In one interprovincial study regarding caregivers (Giesbrecht et al., 2012), the perspectives of Saskatchewan caregivers and their healthcare providers were unsought and overlooked, as Manitoba was chosen to be
representative of all prairie provinces in their data collection. Therefore, it was critical to report what Saskatchewan caregivers need for support in their role by giving them a voice, listening to their experiences and perspectives, and disseminating analyzed findings to the wider community of stakeholders, decision-makers, and service providers in the province.

Relevance to Nursing

Caregivers need to feel supported by healthcare professionals, in addition to family, friends, and community. Regardless of setting, nurses are involved in every almost every aspect in the care of patients and families. Home care nurses are often in regular contact with the caregivers to older adults and are positioned to assess the caregiver-care recipient dyad on a regular basis for the quality of the caring relationship and can monitor for caregiver role strain (Van der Lee et al., 2014). For nurses in acute care settings, an understanding of the caregiving role can allow nurses to acknowledge the range of emotions and feelings that may be experienced by caregivers (Svavarsdottir & Sigurdardottir, 2013). This knowledge and understanding can be applied in cases such as when a caregiver’s care recipient is admitted into the hospital.
CHAPTER 2: SCOPING REVIEW

Author Note

This scoping review has been published and this chapter is adapted from the publication “Caregivers to older adults require support: A scoping review of their priorities,” by S. Hall, N. Rohatinsky, L. Holtslander, and S. Peacock, 2022, Health and Social Care in the Community, 30(6) (https://doi.org/10.1111/hsc.14071). Copyright 2022 by John Wiley & Sons. Reprinted with permission.

Introduction

A third of Canadians aged 80 years or older have been reported to have at least four chronic conditions (Charles et al., 2017) and the vast majority of older adults who are chronically ill rely on informal caregivers seven days a week (Statistics Canada, 2020a). In fact, the majority of care services are provided informally by family members or friends, rather than healthcare professionals (Barello et al., 2019). A concept analysis by Hermans and Mastel-Smith (2012), comprehensive of nursing, sociology, and psychology perspectives, recognizes caregiving as a process of helping another person in physical, mental, emotional, and social domains when they are unable to do so for themselves. Taking on a caregiving role is extremely complex and one thing that is clearly recognizable from research, policy, and practice, is that caregivers require support.

New and experienced caregivers alike may experience difficulty accessing assistance, community resources, support, and adequate finances (Garcia-Ptacek et al., 2019). Therefore, the necessity of developing accessible and acceptable services that address the range of needs is critical to assisting this population (Harrop et al., 2014). However, the priorities caregivers have for support must align with the services being developed. Upon reviewing the literature, we found that previous research initiatives have engaged caregivers in developing specific priorities for support. These research initiatives, along with other methods of needs assessments, are often conducted with the intention of providing direction for the development of support services and interventions (Zarit, 2018).

Support needs are diversely prioritized in different geographical and contextual settings (Henning-Smith et al., 2019; Morelli et al., 2019) and services to support caregivers continue to grow (Reyes et al., 2021). Over the last several decades, research has been conducted worldwide to find better ways to support caregivers in their role (Zarit, 2018). However, to the best of our
knowledge, there has yet to be a collation of caregiver-identified priorities for support. As the caregiver experience affects so many individuals worldwide (Alzheimer’s Disease International, 2021), a scoping review of caregiver identified priorities is justified. The purpose of this scoping review is to provide a comprehensive picture of what caregivers have indicated as their priorities for support.

**Methods**

This review was conducted based on the six-step iterative methodology for scoping reviews outlined by Arksey and O'Malley (2005) and advanced by Levac et al. (2010). This methodology was appropriate for this review, as the purpose was to identify and summarize the extent of evidence relating to caregivers’ priorities for support. The specific methods for this scoping review are outlined herein: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; and (5) collating, summarizing, and reporting the results. The sixth optional step of stakeholder consultation was excluded as it was not the intended aim of the present review. The methods for this scoping review are reported in accordance with the PRISMA-S checklist (Rethlefsen et al., 2021).

**Step 1: Identifying the Research Question**

This review sought to answer the following research question: “What services do caregivers identify and prioritize for support?” By answering this research question, we begin to address the lack of collating existing research on caregiver support priorities.

**Step 2: Identifying Relevant Studies**

**Electronic Databases**

A search strategy was developed to scope the current state of the literature on the caregiver-identified priorities for support. Three databases were searched on July 2, 2021: MEDLINE (OVID interface), CINAHL (Cumulative Index to Nursing and Allied Health Literature; EBSCO interface), and APA PsycINFO (OVID interface). These three databases were selected due to their focus on nursing and allied health sciences that conduct social science research. In consultation with a health sciences librarian, these databases were deemed the most appropriate for this review. The search strategies for each database are presented in Appendix A. Study registries were not searched for this review, as they were not within the scope of this review and not relevant to the research question.

**Reference Lists**
Arksey and O’Malley (2005) recommend checking the bibliographies of studies found through database searches. Therefore, after reviewing all records retrieved through the search of the three electronic databases, CitationChaser software (Haddaway et al., 2021) was used to complete backward and forward citation chasing. Backward chasing involves reviewing records on the reference lists of included studies and forward chasing involves reviewing records that have cited the included studies (Haddaway et al., 2021).

**Grey Literature**

Grey literature was not searched for this review, as the intended goal was to include published peer-reviewed studies only. As part of the exclusion criteria, conference proceedings, online resources, and websites were not sought.

**Search Strategy**

Search strategies are presented in Appendix A. Since the aim of the review was to retrieve studies that caregiver-identified priorities for support, the strategy was narrowed to using only the truncated term “Priorit*.” An attempt at including the terms “needs” and “support” was made; however, despite filters for adjacency, too many irrelevant records were being retrieved, as many studies mention “caregiver needs” or “caregiver support” without developing priorities. Age filters were not used in the search strategy due to the risk of not capturing relevant studies. No date limits were imposed on the search as the goal was to retrieve all literature related to caregiver-identified priorities for support. Any records that were not available through the University of Saskatchewan library were requested via interlibrary loans.

**Step 3: Study Selection**

The records retrieved from the three databases underwent the three steps that adhere to PRISMA guidelines: title and abstract screening, full-text screening, and extraction (Moher et al., 2009; Page et al., 2021). Records were exported from the databases and uploaded into Covidence systematic review software (Veritas Health Innovation) for review management in the title and abstract screening and full-text screening phases. De-duplication of records was conducted using the automated program in Covidence. Titles and abstracts were screened for relevance. Records that seemingly met the inclusion criteria were moved on to the next step of full-text review. Full texts that met inclusion criteria proceeded to data extraction. As previously mentioned, no date limits were imposed on the search and were not a criterion for exclusion.

The inclusion criteria were:
• Peer-reviewed published original research of any design.
• Sample population of caregivers to older adults, aged 55 and above.
• Priorities for caregiver support are identified by caregivers themselves.
• Published in the English language.

The exclusion criteria were:
• Sample population of caregivers to individuals other than older adults.
• Does not identify priorities for caregiver support.
• Priorities established within the report are not identified by caregivers.
• Protocols, abstracts, editorials, grey literature, and conference proceedings.
• Published in a language other than English.

**Step 4: Charting the Data**

While screening, detailed notes were kept based on relevant criteria being reported within the studies. Included studies were exported from Covidence review software. A data extraction spreadsheet was developed from these notes using Microsoft Excel. The following information was extracted: author, year of publication, place of study, study design, sample size, percentage of sample that was female, average age of caregiver, average age of care recipient, care recipients’ medical condition (e.g., dementia, cancer, etc.), relationship of caregiver to care recipient, method of researcher’s interaction with caregivers (e.g., surveys, interviews, etc.), aim of study, study themes, and priorities identified for caregiver support (see Tables 2.1 and 2.2).

**Step 5: Collating, Summarizing, and Reporting the Results**

Extracted data were prepared into two tables. Tables 2.1 displays the collation of study characteristics. Table 2.2 provides an overview of the study aims, themes, and priorities that were reported in the studies. Articles were inputted into NVivo 12 software (QSR International Pty Ltd., 2018) for inductive content analysis. Content analysis is a systematic and objective means of describing and quantifying phenomena (Downe-Wamboldt, 1992; Sandelowski, 1995a). In the case of inductive content analysis, researchers begin with few preconceptions about the topic and do not have a coding framework in mind (Finfgeld-Connett, 2014). The analysis process starts by studying the raw data and making inferences about creating and organizing codes (Finfgeld-Connett, 2014). Once the data is coded, higher level categories are created by the researcher. In content analysis, categories are counted and tabulated (Paterson, 2012). Therefore, content data analysis strategies are useful in determining the frequency of
categories of data within a body of research (Paterson, 2012). Abstraction is the process used to generate the categories in content analysis, where each category is named by the researcher (Elo & Kyngäs, 2008). Subcategories with similar codes are grouped together and then incorporated into high-level categories (Elo & Kyngäs, 2008).

Codes were inductively created in NVivo 12 software (QSR International Pty Ltd., 2018) and sorted into higher level categories through abstraction and titled based on the grouping of codes that were created for the priorities of caregivers. Table 2.3 presents the codebook created in NVivo 12. A hierarchy sunburst chart (Figure 2.2) was generated to visualize the priorities and their distribution throughout studies. Hierarchy charts in NVivo visualize patterns in coding and the attribute values of cases and files (QSR International Pty Ltd.). Sunburst charts are radial tree maps, where hierarchy levels are presented as rings. The outermost ring represents the lowest level of codes, which works inward towards the overarching categories (QSR International Pty Ltd.). The innermost ring is the top level of the hierarchy, which are the highest level categories (QSR International Pty Ltd.). Each colour represents a different category and the branches extending from the centre circle represent sub-categories and lower-level codes under each category. Categories with more branches indicate higher frequency of mention within the included studies. After the generation of the hierarchy sunburst chart, categories were quantified by the number of aggregated codes (Table 2.3) to create a ranked list of caregiver priorities that were identified in the literature.

**Results**

**Study Selection**

Figure 1 demonstrates the study selection process from databases in the updated PRISMA 2020 flow chart (Page et al., 2021). From an initial 3591 records, a total of 31 articles were initially included for extraction. Backward and forward citation chasing of the 31 articles included for extraction was conducted using CitationChaser software (Haddaway et al., 2021) on July 26, 2021. Backward citation chasing (searching reference lists of included studies) yielded 950 records. Forward citation chasing (searching for records that cite an included study) yielded 382 records. A total of two records from the citation chase process met the inclusion criteria and are included in this review. Thus, a total of 33 articles are included in this review.
Summary of Study Characteristics

Study characteristics are presented in Table 1. Studies that met inclusion criteria come from a wide variety of geographic settings across every continent. Study designs varied from qualitative (n = 18), quantitative (n = 2), and mixed methods (n = 11). Two systematic reviews were included in this scoping review based on the way they presented their findings to identify priority areas for caregivers. In most studies, female participation was greater than 50% (n = 24). Two studies had purposive sampling techniques that only selected one sex. Sinfield et al. (2012) sought to explore the needs of caregivers to males with prostate cancer and had only been able to recruit partners from heterosexual dyads, thus 100% of their sample was female. In contrast, Mahomed and Pretorius (2021) focused their study specifically on the needs of male caregivers to persons living with Alzheimer’s disease. While some studies sought the perspectives of any caregivers to older adults, others were specific to a care recipient’s condition. The most common conditions that the articles focused on were dementia (n = 12), neurological disorders (n = 7), cancer (n = 5), and heart failure (n = 3). Six studies were non-specific to care recipient condition. Methods of data collection within the studies included surveys (online or in person), questionnaires, interviews (often semi-structured), focus groups, workshops, meetings, and psychoeducational interventions.

Summary of Content Analysis

Table 2.2 presents study aims, themes, and priorities identified within the included studies. Table 2.3 presents the NVivo 12 codebook from the content analysis. The order was identified by the number of codes in each high-level category, from most codes to least codes, and is as follows: (1) orientation to role; (2) self-care and respite; (3) adapting healthcare; (4) improved supports; (5) information needs; (6) access to resources; and (7) financial assistance. These categories are the main priorities of caregivers because of the grouping of codes from inductive content analysis into the high-level categories. The high-level categories from the content analysis are described herein. Figure 2.2 presents the sunburst hierarchy chart generated by NVivo 12 software, which provides a visual of the highest-level categories in the centre, subcategories as the second ring, and codes (lowest level) as the outermost ring.

Orientation to Role

Orientation to the caregiving role is described as caregivers learning additional skills, tips, and tricks to facilitate their role. Caregivers report wanting improved home accommodations for care recipients, including adaptations to the home environment and assistive
equipment. More accommodations are prioritized in the study by Lamontagne et al. (2019), where caregivers are not regularly provided help adjusting to their new level of functioning. Lutz et al. (2017) reports the priority of adapting the home environment to safely care for the care recipient after stroke and Aoun et al. (2017) discusses caregivers wanting better access to equipment to help facilitate their role. A commonly expressed experience identified by caregivers in the present scoping review involves adjusting to a new normal. Participants in a study by Condon et al. (2019) share that they need to learn how to adjust to the care recipient losing their previous independence. In the study by Sverre Vigeland et al. (2016), caregivers prioritize maintaining a sense of normalcy despite the life changes that accompany the caregiving role. Participants also describe the importance of, and challenges with finding balance between caregiving, work, and personal life demands (Bressan et al., 2020; Doherty et al., 2016; Halkett et al., 2020; Robinson et al., 2012; Sverre Vigeland et al., 2016).

Most central to this category are the priorities that identify the need for preparation and training for caregiving (Bauer et al., 2019; Bressan et al., 2020; Charles et al., 2017; Hirakawa et al., 2011; Lutz et al., 2017; Robinson et al., 2012; Wingham et al., 2015). The Carer Support Needs Assessment Tool (CSNAT) intervention used in the studies by Aoun et al. (2015) and Aoun et al. (2017) identifies that caregivers prioritize knowing what to expect when entering their role. Other priorities identified are developing an understanding of the care recipient’s illness (Aoun et al., 2015; Condon et al., 2019; Dal Bello-Haas et al., 2014; Dovi et al., 2020; El Masry et al., 2013; Elliott et al., 2017; Halkett et al., 2020; Novais et al., 2018; Wingham et al., 2015), understanding facilitators to the care recipient’s health (Hirakawa et al., 2011), general problem solving (Condon et al., 2019; Wingham et al., 2015), and learning first aid (Hirakawa et al., 2011).

**Self-Care and Respite**

Self-care (taking care of one’s physical and mental well-being) and respite (receiving a break from caregiving duties) is the second most prominent category. Priorities related to forming connections with peers, family, and friends, and sharing experiences were identified. Grassel et al. (2010) and Teahan et al. (2021) both report that caregivers prioritize having the ability to exchange stories and experiences with each other in support group settings, resulting in better coping. Bressan et al. (2020) and Doherty et al. (2016) find that caregivers also prioritize feeling supported by family and friends. Two studies discuss the priority of asking for help when
unable to cope (Condon et al., 2019; Robinson et al., 2012). Regarding self-care, the necessity of managing one’s own health was recognized by caregivers (Condon et al., 2019; Grant & Graven, 2019; Lutz et al., 2017; Thomas et al., 2021). Grant and Graven (2019) report that the top two priorities of caregivers in their study are maintaining self-care activities and maintaining physical, emotional, social, and financial well-being. The stress of the caregiving role can cause a myriad of emotions. Learning to regulate one’s emotions is also a priority for caregivers (Aoun et al., 2017; Aoun et al., 2015; Condon et al., 2019).

Respite and receiving a break from caregiving is mentioned in several studies (Dovi et al., 2020; Keogh et al., 2021; Mahomed & Pretorius, 2021; Oliveira et al., 2020; Oliveira, Zarit, et al., 2019; Teahan et al., 2021). Grant and Graven (2019) and Sverre Vigeland et al. (2016) are more specific, with caregivers prioritizing receiving assistance with caregiving responsibilities, rather than managing the responsibilities independently. Other studies report that caregivers prioritize having some short-term time to themselves (Aoun et al., 2017; Aoun et al., 2015; Leslie et al., 2021; Teahan et al., 2021). Lastly, El Masry et al. (2013) reports that caregivers prioritize having a sense of independence in life away from their care recipient.

**Adapting Healthcare**

Caregivers advocate for adaptations to healthcare to meet caregiver and care recipient needs. They want to see flexibility of services (Seddon et al., 2004) and improved continuity of services (Lamontagne et al., 2019; Oliveira, Zarit, et al., 2019). Caregivers believe that healthcare providers need to better include them in communication (Leslie et al., 2021; Wingham et al., 2015) and assess them for their needs in addition to the needs of the care recipient (Lambert et al., 2019; Sinfield et al., 2012; Thomas et al., 2021). To receive better support from the healthcare system, caregivers also prioritize healthcare providers needing to be more empathetic and understanding of how taxing it is to be a caregiver (Bauer et al., 2019; Lambert et al., 2019; Oliveira, Zarit, et al., 2019). The need for empathy is coupled with the call for culturally appropriate care (Katbamna et al., 2017) and with the context of dementia, the need for dementia-friendly spaces (Lamech et al., 2019; Mahomed & Pretorius, 2021).

Caregivers prioritize the need for community awareness and support as well as reducing the stigma surrounding their role (Bauer et al., 2019; Oliveira, Zarit, et al., 2019; Teahan et al., 2021). Caregivers in studies by Thomas et al. (2021) and Teahan et al. (2021) prioritize the need for policy reform to address caregivers. Lastly, Bauer et al. (2019) and Dal Bello-Haas et al.
(2014) find that caregivers felt the process of receiving a diagnosis for their care recipient needs improvements, such as expedition of time from assessment to diagnosis, as well as clarity of information and sensitivity when receiving a diagnosis.

**Improved Supports**

Caregivers call for the prioritization of improved supports. Emotional support for caregivers is iterated as a priority in studies by Bauer et al. (2019) and Condon et al. (2019). Increased access to support in general is identified in many studies as a necessity (Dal Bello-Haas et al., 2014; El Masry et al., 2013; Elliott et al., 2017; Katbamna et al., 2017; Lamontagne et al., 2019). Formalization of supports and interventions, as well as improved quality, is mentioned in four different studies (Charles et al., 2017; El Masry et al., 2013; Keogh et al., 2021; Wingham et al., 2015). The need for psychoeducational interventions are identified, which include exploring the caregiver’s self-care needs, family relationships, and future expectations for caregiving (Mahomed & Pretorius, 2021; Novais et al., 2018). Grassel et al. (2010) and Teahan et al. (2021) call specifically for more access to support groups for caregivers, while Dovi et al. (2020) calls for emotional support in the form of increased peer-to-peer (i.e., caregiver-to-caregiver) interaction.

**Information Needs**

Obtaining general information about the disease of the care recipient is a priority in several studies (Dovi et al., 2020; Elliott et al., 2017; Grassel et al., 2010; Hirakawa et al., 2011; Lamontagne et al., 2019; Sinfield et al., 2012; Sverre Vigeland et al., 2016; Wingham et al., 2015). Caregivers prioritize information: regarding the disease process of the care recipient (Dovi et al., 2020; Elliott et al., 2017; Wingham et al., 2015); from other caregivers about their experiences (Grassel et al., 2010); on formal care services that are available for support (Hirakawa et al., 2011; Lamontagne et al., 2019; Wingham et al., 2015); and/or easier access to general information on caregiving (Sinfield et al., 2012; Sverre Vigeland et al., 2016). Other studies call for access to personalized information to better facilitate specific caregiving scenarios (Bressan et al., 2020; Katbamna et al., 2017; Oliveira et al., 2020; Thomas et al., 2021). For example, Katbamna et al. (2017) report that caregivers prioritize receiving culturally appropriate information that is specific to their care recipient’s discharge from the hospital, what hired care workers can offer the care recipient, and what financial supports may be available to them.
Access to Resources

Although access to resources is embedded through many other categorized priorities already described, this category depicts specific resources that caregivers requested. The resources that caregivers prioritize include assistance with transportation (Lamontagne et al., 2019), end-of-life resources (Lambert et al., 2019; Robinson et al., 2012), and the need for a system navigator role to facilitate access to resources (Charles et al., 2017; Lutz et al., 2017). Both Charles et al. (2017) and Lutz et al. (2017) also report that caregivers prioritize the centralization of resources. Beyond the role of a system navigator, other studies report that caregivers prioritize receiving general support to navigate the complexities of the healthcare system (Doherty et al., 2016; Thomas et al., 2021).

Financial Assistance

Financial assistance encompasses financial support, as well as support in employment. Five studies cite that caregivers prioritize the need for financial support to facilitate their role (Keogh et al., 2021; Lambert et al., 2019; Lamech et al., 2019; Oliveira et al., 2020; Teahan et al., 2021). Keogh et al. (2021), Oliveira et al. (2020), and Teahan et al. (2021) highlight the economic impacts recognized by caregivers, including the strain of the caregiving role on finances and employment. Lambert et al. (2019) discuss the direct costs of caregiving and the financial impact it has on caregivers as a priority for policy reform and research in cancer care. Lamech et al. (2019) asserts that caregivers prioritize cost-effective services to assist them in their caregiving role, such as access to medication and additional health services. Participants in the study by Teahan et al. (2021) call for caregiver allowance, support grants, and monthly wages. Regarding employment, Seddon et al. (2004) discuss the need to support caregivers in the workplace, for example, when they need time off for their caregiving duties. Therefore, the specific priority highlighted by caregivers is to create links with employers to ensure support in their role.

Discussion

The aim of this scoping review was to describe what caregiver-identified priorities exist in peer-reviewed literature. Interestingly, caregivers prioritized better orientation to the caregiving role, both at the beginning of the caregiver experience and throughout the experience itself. This category provides direction for the implementation of programs such as first aid and safety training and education regarding the care recipient’s illness, as well as how to maintain
wellness. Regarding self-care and respite, the need for self-reflection and growth when in the caregiving role is evident. Respite, as a service, covers a spectrum of possibilities ranging from home care services, to adult day care, to short-term stays in long term care facilities (Hanson et al., 1999). As an outcome, respite is seen to provide relief for the family carer, both physically and psychologically (Hanson et al., 1999). Concepts beyond receiving a break, such as learning how and when to ask for help and how to process difficult events were encompassed within this priority, highlighting the importance of prioritizing psychological respite. Interestingly, it has been previously reported that some caregivers identify their employment as a method of receiving this psychological respite (Bijnsdorp et al., 2021; Joseph & Joseph, 2019). Joseph and Joseph (2019) reported in their results that the employment space of caregivers was an “escape, [or] different world” (p. 1486) that facilitated psychological respite, which contributed to a sense of well-being. Bijnsdorp et al. (2021) had similar findings and added that support from supervisors and colleagues was critical to the facilitation of psychological respite in the workplace. Future research could develop tools and a plan of action for workplace supervisors in the workplace to give caregivers the support they need.

Adaptations to the healthcare system are required to better meet the needs of caregivers. Involvement of the caregiver in the healthcare provider’s assessment of the care recipient was prevalently mentioned throughout studies. Although becoming more prevalent in primary care, few studies in settings outside of primary care have examined the feasibility and uptake of caregiver assessment in clinical practice (Riffin et al., 2020). This finding highlights a need for adaptation of the acute care system to involve caregivers in the assessment, diagnosis, planning, intervention implementation, and evaluation of their care recipient’s medical care. Primary care practitioners must also recognize their position to provide information, advice, and emotional support by engaging with caregivers (Wangler & Jansky, 2021). They are also well-positioned to gauge the caregiving situation and anticipate needs for future care (Wangler & Jansky, 2021).

The information needs of caregivers blends itself with the previously mentioned need for orientation to the caregiving role. Another scoping review of information needs identified by caregivers to persons with dementia found that the most commonly reported information needs focused on disease education, care provision, available healthcare services, and caregiver self-care (Soong et al., 2020). The information needs uncovered in the scoping review by Soong et al.
(2020) align with the literature within my scoping review, further emphasizing the importance of information needs as a caregiver-identified priority.

Access to resources has been previously mentioned as an overlapping challenge in other priorities. However, it warrants its own specific attention. Improved access to the resources available to caregivers was encompassed within this priority. The lack of access and knowledge of support interventions has previously been identified in qualitative studies of the caregiver experience (Hall & Holtslander, 2022). Therefore, it is a noteworthy priority to be addressed when preparing, offering, and delivering support services to caregivers. A liaison role to assist in care navigation was mentioned within the included studies in this review. Care navigation and coordination are approaches to personalized management to help facilitate delivery of care (Bernstein et al., 2019). Therefore, exploring how the role can be applied to caregivers specifically may enhance outcomes for the caregiver’s physical and mental wellbeing, as well as caregiver self-care.

The last ordered caregiver-identified priority was financial assistance. It comes as no surprise that caregivers can struggle financially when acting in their caregiving role (Koumoutzis et al., 2021). Furthermore, the toll caregiving can take on a caregiver’s employment status can be taxing and detrimental (Boumans & Dorant, 2021). Caregivers are often juggling their work and caregiving responsibilities, with varying levels of workplace support, which was iterated by Bijnsdorp et al. (2021) in their discussion of psychological respite. Approximately half of all Canadian caregivers are also within the age range of 45 to 65, which are considered prime earning years (Carers Canada, 2021). It is not uncommon for caregivers to be forced to choose between keeping their employment and acting as an informal caregiver (Carstairs & Keon, 2009; Peacock et al., 2020). The result is a need for financial assistance to mitigate the financial distress that informal caregivers may experience due to caregiving duties (Lee & Zurlo, 2014). As well, there is a loss of a potential place for respite, as previously discussed.

**Gaps in Literature**

Throughout the included studies, priorities have been identified for caregiver support. Although these studies have been conducted in many areas across the globe, only one explored the caregiver experience in a rural setting. An exploration of informal caregiver experiences in both urban and rural settings would be unique and valuable to describe if and how priorities differ between the two settings. Furthermore, the experiences and perspectives of the caregiver
experience were often delineated in the included studies from the priorities being set. As well, many studies either neglected or had little mention of the positive experiences of caregiving. The positive aspect of caregiving, such as satisfaction and a sense of meaning, could provide the opportunity to set priorities on how to optimize and sustain these positive feelings toward their role. Since this scoping review focused on priorities for support, a gap that exists in these studies is direct solutions to the caregiver-identified priorities. However, the aims of the included studies were not to develop solutions, but rather provide direction for the future creation of solutions.

**Future Research**

This synthesized list of priorities should not be viewed as a ‘one size fits all’ solution to understanding the support priorities of caregivers in every setting. However, it does lay groundwork for direction for future studies to analyze the support priorities of caregivers in different and unique geographic settings, such as urban, rural, and remote areas. This comparison was not present in the included articles. Therefore, an analysis of urban versus rural priorities is vital to growing the knowledge of what caregivers identify as priorities for support. Researching how to implement these support priorities in policy and clinical practice is necessary to improving outcomes for caregivers.

**Practice Implications**

An understanding of what caregivers prioritize for support is essential. The resources clinicians provide to caregivers must match caregiver wants and needs. Therefore, an assessment of a caregiver’s priorities for support is critical to ensure the facilitation of their role in providing informal care. Facilitating caregiving by supporting caregivers in their role can reduce burden on an overworked and often underfunded system. At the individual level, providing support to caregivers can enhance the mental wellness of the caregiver and promote healthy lifestyles and self-care.

**Strengths and Limitations**

**Strengths**

A strength of this scoping review is that rigorous and transparent methods were used and reported throughout the process. The PRISMA-S reporting items (Rethlefsen et al., 2021) are all presented within this review. The search strategy was developed after salient immersion in caregiving literature and was reviewed by a health sciences librarian experienced in knowledge synthesis and scoping reviews. In the scoping review methodology by Arksey and O'Malley
hand-searching bibliographies of included records is a recommended step. In this review, bibliographies were reviewed by automated software (backward citation chasing) to ensure comprehensiveness, accuracy, and precision. Furthermore, forward citation chasing was conducted, which is often not feasible without automated software. The use of Covidence review management software ensured that all citations were properly accounted for during the review process.

**Limitations**

Although I provide a synthesized list of priorities, it could be hard to argue that these priorities are that of caregivers in every geographic area. The political context, culture, and existing supports for caregivers can alter the support priorities of caregivers. Database selection may have been a limitation in the review, as only three databases were chosen. As well, grey literature and study registries were not searched as the intent of the review was to collate peer-reviewed and published evidence only. However, the exclusion of grey literature and study registries is a common limitation, as it is often unrealistic to retrieve and screen all the relevant literature due to the broader focus of scoping reviews (Pham et al., 2014). The lack of critical appraisal of the included studies is one of the primary limitations of scoping reviews. With that being said, the emphasis of a scoping review is on comprehensive coverage, rather than on a particular standard of evidence (Pham et al., 2014). By not addressing quality appraisal, this scoping review was able to cover a greater breadth of study designs and methodologies than a systematic review. Lastly, because this review only included English-speaking literature and the search strategy was conducted using only English terms, our results may have been limited by the exclusion of caregiver-identified priorities from non-English literature.

**Conclusion**

This scoping review provides a synthesis of priorities from several geographic locations. Previous research efforts that have engaged caregivers in setting priorities for their support have identified directions for facilitating the support and well-being of this essential population. This scoping review provides a collation of this literature and presents a synthesized list of caregivers’ priorities for support. When support priorities are identified by caregivers themselves, there is likely a stronger chance of uptake and use of support interventions. Policymakers, healthcare professionals, governmental and non-profit organizations can use evidence from this study to guide decisions when developing support interventions for caregivers.
CHAPTER 3: METHODOLOGY AND PROCEDURES

Study Design

In this thesis work, caregivers to older adults participated in an online qualitative survey. The qualitative approach underpinning this study is qualitative description (Sandelowski, 2000, 2010). The data collection method was informed by the literature on qualitative surveys provided by Braun et al. (2020). The content analysis method by Elo and Kyngäs (2008) guided qualitative data analysis.

Qualitative Description

Qualitative description (Sandelowski, 2000, 2010) was the methodology underpinning this study. Qualitative descriptive studies offer comprehensive summaries of events and seek descriptive validity of the meanings which participants assign to those events (Sandelowski, 2000). Describing the meanings that participants ascribe to a certain phenomenon is a component of qualitative description. In the case of this study, the phenomenon of interest was caregiving. Qualitative description also allows for study findings to be close to the data (Sandelowski, 2000). Being close to the data was critical in this project as the goal was to describe the experience of caregiving in Saskatchewan.

Sandelowski (2000) asserts that qualitative description is an appropriate method when researchers are seeking an accurate account, through straight description. Although less sophisticated than methods such as grounded theory or phenomenology (Sandelowski, 2000), qualitative description is an excellent method for junior qualitative researchers (Latifnejad Roudsari, 2019). Its philosophical orientation involves a pragmatic approach, based on practical considerations rather than theoretical considerations (Neergaard et al., 2009). However, there are overtones of other qualitative approaches, including phenomenology, grounded theory, ethnography (Neergaard et al., 2009) and descriptive summaries yielded from qualitative description can lead to the working hypotheses or key categories for future theory-based research (Sandelowski, 2000). The qualitative descriptive method aligned with this thesis study, where the purpose was to explore and describe the experiences of Saskatchewan’s caregivers to older adults.

Naturalism and Naturalistic Inquiry

Various qualitative methods are used in health research, but they all share an orientation towards naturalism (Green & Britten, 1998). Naturalism is the understanding of health behaviour
in everyday context and involves exploring the complexities of behavioural contexts such as barriers to healthcare behaviours and the antecedents and consequences of behaviour (Green & Britten, 1998; Newton, 2000). Further, naturalism is a commitment to studying a phenomenon in a manner that is free from duplicity or the inventiveness of the researcher (Sandelowski, 2000, 2010). The qualitative descriptive methodology draws from tenets of naturalistic inquiry, meaning the phenomenon is studied in its natural state (Bradshaw et al., 2017; Sandelowski, 2000). Researchers attest that an understanding of the alignment between qualitative description and naturalistic inquiry offers a practical way to explore and answer research questions (Cutler et al., 2021). In any naturalistic study, there is no pre-selection of variables, no manipulation of variables, and no a priori commitment to any certain theoretical view of a target phenomenon (Sandelowski, 2000, 2010). Data are acquired from studying real-world settings to inductively construct patterns, categories, and themes (Patton, 2005).

**Strengths and Limitations**

All methods have limitations and qualitative description is sometimes referred to as the “poor cousin” of more developed qualitative methods (Neergaard et al., 2009) and often criticized for not having a basis of theory (Milne & Oberle, 2005). With that being said, this criticism is invalid when the description of a phenomenon is desired (Neergaard et al., 2009). Strengths of qualitative description include the emic perspective where participants decide what is important, rather than the researcher (Milne & Oberle, 2005). In other words, data is participant driven. It is authentic, as the informants perspectives are accurately represented through data-driven coding, categorizing, and theming (Milne & Oberle, 2005). Moreover, it has enhanced credibility by capturing and portraying the true insider perspective (Milne & Oberle, 2005). Ultimately, integrity and neutrality are the most important criteria to ensure when using the qualitative descriptive method (Lincoln & Guba, 1985; Milne & Oberle, 2005).

**Setting and Sample**

**Setting**

The setting for this study was the Province of Saskatchewan. Saskatchewan offers a diverse geographic profile with both large and small urban centres. A list of the top 15 population centres is presented in Table 3.1. These centres were the targeted major areas for the recruitment of this study’s sample. In Canadian geography, rurality is defined based on different criteria, such as population size, density, labour market, settlement context, and delivery mode
assigned by Canada Post (du Plessis et al., 2002). In this thesis study, participants self-identified their living situation as urban large, urban small/medium, or rural.

**Sampling Strategy**

Purposive maximum variation sampling methods were used to recruit caregivers to older adults (aged >55 years for this study) via community newsletters, an online Facebook post in Saskatchewan community Facebook groups, and a paid Facebook advertisement. A member of the Saskatoon Council on Aging’s Caregiver Committee generously translated all study materials to be inclusive of the Francophone community in Saskatchewan. Figure 3.1 depicts the recruitment message that was distributed among these avenues. The Facebook groups that were targeted for recruitment are presented in Appendix B, although not every Facebook group allowed the post to be shared as per their community guidelines. Primary, secondary, and tertiary caregivers were all welcome to participate in this study; however, the levels of caregivers were not described to participants. Rather, the recruitment materials stated, “All persons with any level of involvement in caregiving to older adults are welcome to participate.” No restrictions were imposed on what the relationship of the caregiver was to the care recipient. Bereaved caregivers were also welcomed to participate in the survey. The survey was also translated to French by Janice Thomas, the director of the group Entr’elles, to facilitate the inclusion of Saskatchewan’s French (Fransaskois) community.

**Sample Size**

Maximum variation sampling is a type of purposive sampling that is frequently employed in qualitative nursing research (Sandelowski, 1995b). Sandelowski (1995b) describes that the researcher will require more numbers of sampling units to reach informational redundancy or saturation when there is more variability within the confines of a qualitative project. There are two kinds of variation that are considered for this study: demographic and phenomenal variation (Sandelowski, 1995b). Demographic variation is where variation is sought on people-related characteristics and phenomenal variation regards the variation on the target phenomenon under study (Sandelowski, 1995b). The decision to seek any kind of variation is made apriori to have representative coverage of variables that the researcher assumes to be important in understanding how diverse factors come together as a whole (Sandelowski, 1995b). In similar studies that implemented open-ended qualitative surveys with caregivers to older adults, whether online or via mail, sample sizes were between 46 and 825 participants (Aoun et al., 2017; Aoun et al.,
The average sample among these cited studies was 389 participants. Therefore, the initial target sample size for this thesis study was 200 participants, to estimate adequately capturing the demographic variation (age, training, years of experience) and phenomenal variation (relationship to care recipient, care recipient condition) that was expected to exist within the province.

Data Collection

This thesis study used a researcher-developed online qualitative survey to collect caregiver demographic and qualitative data. A previous study conducted in rural Saskatchewan used data collection methods of meetings and an open-ended survey that was delivered by mail (Dal Bello-Haas et al., 2014). This thesis study used SurveyMonkey (Momentive Inc., 2021) for feasibility and ease of data collection, which also eliminated the need for postage funds. Collected data was exported into Microsoft Excel files. To safeguard participant responses, internet security measures within the SurveyMonkey interface were described within the consent form. This safeguard included a transport layer security encryption (i.e., HTTPS://) which was active for all submitted responses.

Method of Approach

All recruitment materials were pre-approved by the University of Saskatchewan’s Behavioural Research Ethics Board. The materials included a weblink that directed participants to an online qualitative survey with open-ended questions, hosted on SurveyMonkey under the University of Saskatchewan’s institutional license. The blueprint for the online qualitative survey is presented in Table 3.2. When the link was clicked by a potential participant, a consent form was presented first, where they had the opportunity to review the project’s aims and understand their rights to informed consent. The approved participant consent form is presented in Figure 3.2. Participants agreed to provide consent by clicking the “Continue to Survey” button.

Since the study focused on the experiences of caregivers to older adults, it was expected that many eligible participants would be older adults themselves, such as spousal caregivers. There was some concern regarding whether or not Facebook was an appropriate tool for recruiting older adults. However, a review of Canadian statistics showed that 1 in 3 older adults use social media (Schimmele et al., 2021). Furthermore, Whitaker et al. (2017) conducted a
systematic review of the use of Facebook for recruiting participants for health research. They found that recruitment of older adults through Facebook is feasible and successful. As well, in one of my previous studies, my sample of Saskatchewan older adults from both urban and rural settings reported actively engaging with technology, specifically with social media and Apple iPads (Hall et al., 2021).

Facebook was also an economical method of recruitment. While the social media announcements within the community Facebook groups were posted without cost, a small amount of funding provided by the Saskatoon Council on Aging allowed the employment of a paid advertisement for additional recruitment. These advertisement campaign options offered by Facebook were previously successful in recruiting research participants. Ali et al. (2020) used a web-based survey for data collection and advertised on Facebook. The total reported cost of the advertisement was $906 USD, which cumulatively reached 236,017 individuals and resulted in 9609 link clicks (Ali et al., 2020). Almost a third of respondents (28.5%) were over the age of 60 years. For this study, $200 CAD was invested in two paid Facebook advertisements, which reached a total of 26,876 individuals in Saskatchewan, and received 1414 link clicks.

**Demographics**

Demographic data were collected before the qualitative questions in the survey. Participants who accessed the survey were asked to provide the following demographic information: first three digits of their postal code for later data presentation of geographic distribution (see Figure 4.2), self-identified urban or rural setting, age of caregiver, age of care recipient, years of caregiving experience, whether training was received for the caregiving role, relationship to care recipient, and care recipient condition.

**Online Qualitative Survey**

Traditional data collection techniques in qualitative research include direct face-to-face interviews, free-flowing conversation, and building rapport with participants (Moises, 2020). However, online qualitative surveys can harness the rich potential of qualitative data and the option for online delivery offers much opportunity to qualitative researchers (Braun et al., 2020). Preconceptions exist regarding qualitative surveys, as it differs from the traditional technique in the qualitative paradigm of participant engagement. Braun et al. (2020) challenge these preconceptions of qualitative surveys and argue that qualitative surveys are an exciting and flexible method with several applications and advantages for both researchers and participants.
The benefits of online qualitative surveys are abundant during the COVID-19 pandemic, where data collection has become more difficult due to public health orders, social distancing, and isolation requirements (Ali et al., 2020; Moises, 2020).

Online qualitative surveys are upcoming technique for qualitative data collection (Braun et al., 2020). They are also feasible and low cost (Braun et al., 2020; Nayak & Narayan, 2019). There are several benefits to online qualitative surveys described in the literature. The online qualitative survey technique is found to be more enjoyable to participants due to its shorter duration (Nayak & Narayan, 2019). The necessity of data entry is eliminated allowing for a decrease in processing costs while still allowing standardization and anonymity (Nayak & Narayan, 2019). Previous published literature stands testament to the justification that the online qualitative survey technique is acceptable for this proposed study. In a study by Whitehead and Torossian (2021), 825 older adults (>60 years) completed an online qualitative survey to gather the experiences and perspectives of older adults during the COVID-19 pandemic. The questions that older adults responded to were “What are you finding most challenging or stressful today?” and “What is bringing you joy or comfort today?” (Whitehead & Torossian, 2021, p. 38). These questions are of similar genre to the questions for this study, presented in Table 3.2.

In another example, an international study by Chevance et al. (2020) used an online survey with open-ended questions to collect data from patients, caregivers, and healthcare professionals. Their survey sought to identify participants’ priority outcomes for the treatment of depression. Questions for caregivers included: “What do you consider to be the most difficult aspects to live with for your family member/friend with depression?” and “What do you consider most important to address in a depressed person?” (Chevance et al., 2020, p. 694). A total of 464 caregivers, with a mean age of 45 years completed the survey by Chevance et al. (2020), with 22% of respondents being over the age of 50 years.

In a study conducted in Ontario, Canada by Bainbridge et al. (2018), the qualitative comments of bereaved caregivers were collected in an online survey. In their survey, caregivers reported what was positive and negative about the services provided during the last three months of their care recipient’s life as separate open-text responses. The questions were “What if anything was good about the care?”, “What if anything was bad about the care?”, “What would you keep about the care provided?”, and “What would you change about the care provided?”
A total of 550 caregivers participated in the online qualitative survey study, with 69.8% of the sample (n=380) being >70 years of age.

Online qualitative surveys also align with the qualitative descriptive design. An example of this, albeit unrelated to caregiving, is the study by Hart and Mareno (2014) that explored challenges and barriers to culturally competent care through the voices of nurses. In their study, Hart and Mareno (2014) used open-ended surveys to give their participants an opportunity to describe their perception of challenges and barriers in the provision of culturally competent care. A total of 374 nurses participated in the study by providing descriptions or comments within the open-ended questions (Hart & Mareno, 2014). Using thematic analysis (Braun & Clarke, 2006), Hart and Mareno (2014) were able to create three themes from the collected data. Since the purpose of this study was to describe the experiences and perspectives of caregivers from across the province of Saskatchewan, the online delivery of a qualitative survey facilitated data collection across a large geographic area.

**Study Survey**

As previously iterated, Facebook had been found to be a successful method of participant recruitment, and this was inclusive of the older adult population (Whitaker et al., 2017). Social media platforms, such as Facebook, allow for widespread dissemination of online qualitative surveys. Online surveys are also easily created with software such as SurveyMonkey, Google Forms, or Qualtrics, and many institutions subscribe to survey development tools to facilitate students and faculty conducting survey-based research (Moises, 2020). The University of Saskatchewan has an institutional subscription to SurveyMonkey to support teaching, learning, research, and administration (University of Saskatchewan, 2019), which is why this study used SurveyMonkey to host the data collection.

Of the 34 studies in the scoping review conducted in Chapter 2, seven studies used surveys as their method of interaction (Aoun et al., 2017; Aoun et al., 2015; Bauer et al., 2019; Grant & Graven, 2019; Grassel et al., 2010; Lambert et al., 2019; Seddon et al., 2004). Two of these studies used a validated survey instrument (Aoun et al., 2017; Aoun et al., 2015); however, the rest of the studies employed researcher-developed surveys that were crafted to address the specific research questions of the studies. These surveys were reviewed and informed the four open-ended survey questions for this study that were developed to address the two
aforementioned research questions. A blueprint of the online qualitative survey is presented in Table 3.2. The four open-ended survey questions were:

1. What do you find most challenging about being a caregiver?
2. What do you find is positive about your caregiving role?
3. What do you think is most important for support in your caregiving role? In other words, what are your top priorities for support?
4. Is there anything else you would like to add about the experiences, perspectives, and priority support needs of caregivers in Saskatchewan?

Prior to fully launching the survey, five caregivers from SCOA’s Caregiver Committee reviewed a pilot draft of the survey. Feedback was sought based on the language of the survey, length of time to complete the survey, and the survey’s overall structure. Data collected from the pilot participants was retained for the study itself. The pilot participants shared that they did not have any concerns with the survey. The online qualitative survey was then launched on June 2, 2022, and remained available until July 20, 2022. The recruitment post posted in the community Facebook groups in Appendix B with permission from the groups’ administrators on June 2, 2022, and July 2, 2022. Paid advertisements were launched on June 10, 2022, and July 6, 2022. To our knowledge, the recruitment materials were included in a total of three newsletters outside of the Facebook recruitment.

Data Management

Data corpus refers to all data collected for a research project and data set refers to the data from a corpus that are being used for analysis (Braun & Clarke, 2006). This thesis study had two data sets within its data corpus: demographic data and qualitative data. After closing the survey, responses were exported from the SurveyMonkey interface into a Microsoft Excel file. Demographics were tabulated in Microsoft Excel and tables were developed to adequately demonstrate the demographics of respondents. Open-ended responses to the four main survey questions were compiled into a Microsoft Word document and imported into NVivo 12 software (QSR International Pty Ltd., 2018) for qualitative coding and directed content analysis (Hsieh & Shannon, 2005).

Data Analysis

Content analysis is a method of analyzing written, verbal, or visual communication messages (Elo & Kyngäs, 2008). Qualitative content analysis focuses on the content or
contextual meaning of data (Hsieh & Shannon, 2005). Data for this project was collected in text-form through narrative responses to open-ended survey questions. Pre-existing research helped to develop and focus the research questions for this study.

Coding schemes are a critical data reduction tool (Miles & Huberman, 1984). At their simplest, codes are labels which help the researcher to later find whatever they may be searching for (Richards & Morse, 2013). With that being said, coding is about linking rather than merely labeling (Richards & Morse, 2013). The process of coding also fractures the data, disaggregating the records and allowing the researcher to look at the data differently, as they are seen through the category rather than the full collection (Richards & Morse, 2013). Coding moves data from diffuse and messy texts to organized ideas about what is going on (Richards & Morse, 2013). Codes are derived from relevant research findings and defined during data analysis (Hsieh & Shannon, 2005). An inductive, bottom-up approach to coding was employed for this study. The following steps, outlined by Hsieh and Shannon (2005), were carried out in this study for the process of content analysis:

1. All survey responses were read by the researcher in their entirety to become familiar with the data. No coding of any type was used at this stage.
2. The next step in the content analysis was to begin the coding process (Hsieh & Shannon, 2005). Survey responses were re-read, and highlighted passages were sorted into low-level codes. These low-level codes were then sorted into higher-level categories.
3. Lastly, rank order comparisons of frequency of codes were used to identify which categories of codes were most prevalent, and subsequently what was most important to caregivers in Saskatchewan (Hsieh & Shannon, 2005).

Rigor and Trustworthiness

Credibility, transferability, dependability, and confirmability are criteria used to ensure rigor (Lincoln & Guba, 1986). Credibility is described as whether the reality of the participants is accurately represented by the researcher (Lincoln & Guba, 1986). To ensure credibility in this study, regular contact was made with my supervisor, Dr. Noelle Rohatinsky while I carried out my data analysis. Furthermore, updates on data collection and analysis were provided monthly at SCOA’s Caregiver Committee meetings. A preliminary review of my results was also completed by my committee. Transferability refers to the generalizability of findings (Lincoln & Guba, 1986), which was achieved through a review of relevant literature, presented in Chapter 2.
Transferability also encompasses the knowledge translation plan outlined further in this chapter, which includes plans to disseminate findings at local, provincial, and national levels. Dependability is described as an audit trail (Lincoln & Guba, 1986), which was accomplished by keeping detailed notes about my analysis process and limitations to the study that I recognized while analyzing the data. Lastly, confirmability was achieved through my salient immersion in the data (Lincoln & Guba, 1986), as I was responsible for reviewing and coding all survey responses in NVivo when conducting the content analysis.

**Ethical Considerations**

Ethical approval was received from the University of Saskatchewan’s Behavioural Research Ethics Board (Beh ID #3377). SurveyMonkey data was collected anonymously. When prospective participants accessed the survey link, a consent form was presented first, where they had the opportunity to review the project’s aims and understand their right to informed consent (Figure 3.2). Those who wished to participate then selected “Continue to Survey” to confirm consent prior to providing their responses in the survey form. Postal code data was used to generate a pinpoint map to show the geographic distribution of participants; however, since only the first three characters were collected, the pinpoints in Figure 4.2 only demonstrate the general area of the participants so that anonymity is protected. Any names of healthcare professionals, facilities, community programs, and locations were redacted when a response was included in the thesis. Collected data is currently stored on the University of Saskatchewan’s secure OneDrive server and will be deleted beyond recovery after five years in July 2027.

**Researcher Reflexivity**

I became involved in research in May 2019 through an undergraduate research assistantship in the College of Nursing. My initial work in nursing academia focused on the topic of geriatric oncology. Through my work on several projects, I gained experience in qualitative and mixed methods research, including facilitating focus groups, conducting semi-structured interviews, and analyzing qualitative data. One specific project I worked on was a qualitative descriptive study to explore how older adults with cancer engage with technology to support the self-management of their disease (Hall et al., 2021). This research allowed for me to see how the older adults of today’s age are using technology to support their health behaviours. In the fourth year of my undergraduate nursing education, I began working with caregivers in my community health practicum. I became invested in the health and well-being of caregivers to older adults in
this setting and realized how important of a topic it was to me personally since my mother had been a caregiver to both of my grandparents.

I continued to garner experience in researching aging and older adults through additional research assistantships. Through my work with Dr. Shelley Peacock on the Dementia Champions Canada project (Peacock et al., 2022), I became incredibly interested in the concept of knowledge translation – specifically, communicating research findings to the general public in a way that is easy to understand. In September of 2022, I was hired at the University of Alberta as a Knowledge Translation Specialist for a Public Health Agency of Canada project to support caregivers to older adults living with dementia in long term care (My Tools 4 Care-In Care). My hiring came at an opportune time, as I was in the midst of the data analysis for this thesis study and working concurrently at creating knowledge products for caregivers to older adults helped to focus and inspire me in my chosen field of research.

As a registered nurse, I interact with caregivers on a near-daily basis in my clinical practice. As the son of a caregiver, I know how the caregiver experience can affect one's life in both challenging and positive ways and I recognize the imperative need for support in the caregiving role. I am fortunate to have had much practical research experience in my career thus far. My reflexivity as a junior researcher conducting this study is enhanced by the blending of my life experiences with my growth as a research trainee, which has allowed me to be dedicated and committed to telling the stories of the caregivers who participated in my project.

Knowledge Translation

The scoping review I conducted (Chapter 2) was published in the journal *Health and Social Care in the Community* with my supervisor and committee members as co-authors (Hall et al., 2022). Abstracts for the scoping review were presented nationally at the Canadian Association on Gerontology (CAG) conference in October 2021 and locally at the Saskatchewan Health Research Showcase in November 2021. Furthermore, I conducted what I termed to be a “narrative reanalysis,” where I used less rigorous narrative review methodology to reanalyze a sub-set of studies from the initial scoping review. Through this process, I reanalyzed the included studies from the scoping review that were specific to cancer caregiving. I presented the narrative reanalysis at the International Conference on Cancer Nursing (ICCN 2022) in February 2022 and at the Multinational Association on Supportive Care in Cancer’s (MASCC) 2022 Annual Meeting in June 2022.
To keep the public and participants updated, I have been maintaining an active presence on my Facebook recruitment page, entitled the Sask Caregiver Research Lab. I have been sharing updates throughout the data collection and analysis stages, as well as publications that have risen from my work with caregivers. I will provide a lay summary of the entire thesis work on the same Facebook page. For future knowledge translation efforts, I plan to share my results with the SCOA to provide direction in expanding their caregiver support network within the province. I plan to also contact newsgroups such as the Canadian Broadcasting Corporation (CBC) and Global News for the knowledge translation of results to the general public. I will continue to submit abstracts for different steps of the project (scoping review, preliminary analyses, method replication) to local, national, and international conferences as opportunities arise. Most recently, in February 2023, an abstract of the findings from this thesis was accepted for the Canadian Geriatrics Society’s Annual Scientific Meeting.
CHAPTER 4: FINDINGS

Summary of Demographics

The Saskatchewan Caregiver Experience Study’s data collection closed on July 20, 2022. A total of N=387 responses were received and N=355 respondents met the inclusion criteria. Reasons for exclusion included: being an older adult caregiving to a younger adult (<55 years old), being a healthcare worker but not a family caregiver, or being from a province other than Saskatchewan.

Geography of Participants

The family caregiver participants (herein referred to as participants when discussing the study findings, and caregivers when specifically sharing their survey responses) self-identified the geographic area they live in as rural, large urban, or small/medium urban. They were almost evenly distributed amongst each setting. A pie graph of the geographic locations of participants is presented in Figure 4.1. Since the first three characters of the participants’ postal codes were collected, a map was able to be generated to display the geographic distribution of participants. This map is presented in Figure 4.2.

Participant Characteristics

Participant demographics are presented in Table 4.1. The overall mean caregiver age was 61 years with an age range of 22 to 87 years. The majority of participants were caring for a parent (n=268), followed by those caring for a spouse (n=68). Participants had a mean 8 years of caregiving experience, although the majority of participants in the study had 1-5 years of caregiving experience (n=170). Lastly, only 29% of participants (n=102) within the study had received any form of formal training to carry out their caregiving role. The types of caregiver training received are presented in Figure 4.3. Much of the training received came from jobs held by the participants that happened to support them in their role as a family caregiver. The most common type of caregiver training received was Continuing Care Assistant (CCA) training. The second-most common training was formal nursing training, including Registered Nursing, Registered Psychiatric Nursing, and Licensed Practical Nursing programs. One participant reported to have training as an end-of-life doula, also known as a death doula.

Within this study, six participants had received training that was a specific orientation to their caregiving role, which were described in open-text response boxes on the survey. Most of this orientation was received by caregivers prior to the discharge of their care recipient from a
hospital, and involved specific instruction regarding dressing changes, emptying drains, and physical and occupational therapies. One participant noted they received their training through a Community Living program. Another participant reported receiving education that was specific to their care recipient’s condition by saying “[I received] some training through the Brain Tumour Foundation of Canada. I would describe it more as education. [I] attended conferences and seminars” (caregiver to a spouse with cancer in a large urban setting). The “Other” training reported by participants included leading support groups (n=2), working in group homes (n=2), and being a chaplain in long-term care (n=1). Certification programs reported by participants included the Red Cross Geriatric Care Certification (n=1), Rehabilitation Support Worker (n=2), and internal training from a previous workplace: “I received some training when I worked for a franchise. It was that company’s training program” (caregiver to a friend and a relative in a large urban setting [medical conditions of recipients undisclosed]).

Care recipient demographics are presented in Table 4.2. Care recipients to which the caregivers provided care had a mean age of 83, with an age range of 55 to 104 years. The most common medical condition reported for care recipients was Dementia/Alzheimer’s or related disorders, followed by heart/kidney/lung conditions. Eleven participants chose not to disclose their care recipient’s condition.

Main Findings by Question

The survey asked participants three specific questions regarding the challenges and positive aspects about being a caregiver and support priorities of caregivers in Saskatchewan. Table 4.3 presents the word counts of responses to each question. A fourth open-ended question where participants were able to express anything outstanding about their caregiver experience was also included but responses to this question were not directly related to answering the research questions of this study. Not all participants provided responses to all of the survey questions. The first question (challenges experienced by caregivers) was the most answered question (n=354 of 355), and also elicited the highest number of words in total (n=10327), largest average word count per response (n=29), and had the widest word count range, with the most words in a single response (n=843).

A content analysis (Elo & Kyngäs, 2008) of the main findings from the three main questions in the survey is presented herein. Figure 4.4 presents a mind map of the content analysis for the study, which was derived from organizing the main categories of codes that were
created during content analysis. For each question, overarching categories determined through content analysis are presented in order of prevalence of codes (i.e., the overarching category with the highest number of codes is described first).

**Question 1: Challenges Experienced by Caregivers**

The first survey question asked participants: “What do you find most challenging about being a caregiver?” Overarching categories were determined to be: (1) caregiving is exhausting; (2) “living my own life”; (3) navigating complex systems; (4) “am I doing it right?”; and (5) caregiving at a distance.

**Caregiving is Exhausting**

**Caregiving Demands are Exhausting.** Saskatchewan caregiver participants shared that caregiving is exhausting. Many participants reported the significant time commitment caregiving takes, such as being “always on” with a lack of breaks and respite. The participants used the phrase “on call 24/7” in their responses to this question. The constant demands of caregiving regularly pull participants in multiple directions and mental and physical exhaustion, along with sleep deprivation is very commonly reported. When the participants do get a break, they reported that their thoughts still wander to their caregiving role, with worries of what could be going on with their care recipient (e.g., wondering if their care recipient is doing okay). One caregiver to a spouse with frailty in a rural setting stated: “Trying not to leave him alone but having to attend to other responsibilities like shopping, gardening, snow shoveling in winter, etc.” Another statement from a caregiver to a parent with dementia and a heart/kidney/lung condition in a large urban setting was: “On the rare occasion I have a moment to myself, I’m thinking about mom and her care.” The burden of caregiving is also mentioned throughout the responses to this question and adult children caregiving for their parents felt the role reversal was especially troubling, as they struggled to accept the change in dynamics. “Not getting a break from it. Seeing my mother as more of a burden and less of a parent.” (Caregiver to a parent with frailty, mental illness, and arthritis in a small/medium urban setting). One caregiver in a small/medium urban setting called caregiving a “long haul” in the face of caring for both an aging parent and their spouse.
You are on call 24/7 with little to no down time. Feeding, toileting, bathing, feeding, and moving the person is all very challenging and both mentally and physically exhausting. During caregiving, I broke a toe and a wrist. I was treated for depression and suicide.

-Caregiver to a parent with dementia in a rural setting.

Not getting a full night’s rest and working full time was the most difficult along with caring for my husband who suffers from anxiety and depression… and then my mom needed to be cared for and we moved her here with us from BC as there was nobody to care for her there. It’s been a long haul.

-Caregiver to a spouse with mental illness and a parent post-stroke in a small/medium urban setting

**Caregiving is Emotionally Taxing.** Emotions elicited from the burden of caregiving such as grief, guilt, and hopelessness were mentioned. Sadness and grieving were often reported to be related to loss, such as loss of a social life, or missing “the way things used to be.” Guilt was coupled with feeling inadequate as a caregiver, not having enough hours in the day, and missing out on life events, which participants sometimes felt was disappointing to others in their lives. Time for self-care was another reason for feeling guilty.

Participants also reported feeling guilty when having to place their care recipient in a care home, or long-term care. The “loss of future plans and dreams” or loss of social life and hobbies were contributors to feelings of hopelessness reported by participants. “Caregiver loss of free time and ability to be away from the home for more than short periods. Loss of social life as a couple. Loss of future plans and dreams.” (Caregiver to a spouse with frailty and an acquired injury in a rural setting). Participants report struggling with maintaining their mental wellness, especially when they themselves live with depression and/or anxiety. “I feel so sad most of the time. I also worry a lot as to where I will end up or what I will do when he passes away… unless I am first!” (Caregiver to a spouse with dementia, frailty, vision deficits, and diabetes in a small/medium urban setting).

Trying to meet my dad’s needs and being his main source of emotional support while living in another community and trying to take care of my other family members while working. I constantly feel guilty about not doing enough to meet anyone’s needs, and I
also feel guilty if I take any time for myself. On top of that, I have another family member with disabilities, and human service professionals sometimes suggest that I should be completely responsible for her care too. It is difficult to find supports for elderly parents or others with disabilities, and existing services for both groups are often inflexible and seem eager to “pass the buck” to others.

-Caregiver to a parent with dementia and frailty in a large urban setting.

**Caregiving Can Get Overwhelming.** Participants reported feeling overwhelmed by their caregiving role. Some caregivers noted the importance of trying to remain positive, although the burden of caregiving made this more difficult. “Trying to remain kind and positive when you are absolutely overwhelmed. We all feel consumed by others needs sometimes.” (Caregiver to a parent in a small/medium urban setting [medical condition undisclosed]). Sometimes participants felt invalidated when their care recipient was unappreciative of their efforts, which contributed to the sentiment of feeling overwhelmed. Isolation is felt by participants when they do not have the support of friends and family or feel as though a support network is unavailable to them. Other participants who did have supportive families still felt isolated due to the time that was invested being away from their family to be with the care recipient, which in turn leads to loneliness. “It really is lonely. Being responsible for everything is really hard.” (Caregiver to a spouse with a neurological condition in a rural setting).

**Time Commitment.** The journey of caregiving can feel as though there is no end in sight, which also makes things difficult for participants to plan their lives in advance. Due to the lack of ability to schedule their own lives, participants reported feeling as though there are not enough hours in the day. Working full-time and providing care to a care recipient was found to be especially difficult for participants. With the feeling that there is simply just not enough time to tend to all responsibilities, participants share that they sometimes find themselves having to set boundaries with their care recipient to maintain a sense of self. “Being the lone engaged family member, making it up as I go along, having to set boundaries with care recipients in order not to completely lose myself” (Caregiver to a parent with dementia and a heart/kidney/lung condition in a large urban setting). Overall, it is clear from the responses that the time commitment needed to be a caregiver is what truly exhausts participants the most.
Finding me time. Between my own family and my mom and formerly mom and dad requiring a big chunk of time each day, I have no down time. I have my own health issues that I end up ignoring my medical team’s advice due to not enough hours in the day to rest and do less.

- Caregiver to a parent with dementia in a rural setting.

**Growing Resentment.** With the countless hours invested in caregiving tasks with no pay, and sometimes no thanks, some participants reported becoming bitter and resentful towards the care recipient and/or families. One caregiver to a parent with dementia and cancer in a large urban setting said they felt as though they were being “treated like a non-person.” Other participants reported being regularly ignored by their families and the healthcare professionals they interact with. In these stressful situations, caregivers reported sometimes just needing an ear to listen; however, several reported not knowing how to ask for help, which can be even more problematic when some caregivers themselves report that they’re “getting old too” and “don’t have that many good years of my own left.”

**Watching the Care Recipient Decline.** For participants who had known their care recipient in both sickness and in good health, it was reported that they struggle emotionally watching their care recipient decline. “The anger shown by my wife, who has Alzheimer's, to me, her caregiver. Also, the deterioration…” (Caregiver to a spouse with dementia in a large urban setting). Another caregiver stated: “It’s challenging (and trying) to keep from becoming a parent to my parent. It’s difficult watching independence slip away” (Caregiver to a parent with frailty in a large urban setting). Lastly, another caregiver shared: “The mental duress and heartbreak of ongoing care to someone who declines a bit every day... scared of them continuing to live and scared of them dying. Being their cheerleader and caregiver while inside I am falling apart” (Caregiver to a parent with dementia, a heart/kidney/lung condition, and frailty in a large urban setting).

**Stubbornness and Denial.** Some participants report finding it difficult to accept the care recipient’s condition and others have difficulty getting the care recipient to accept their own condition and the fact that they need help. A handful of participants reported that the care recipients are stubborn and do not want to accept the help that they require as they want to hold onto their independence. Some participants reported restructuring their lives to be able to keep
the care recipient in their original homes. One participant shared that there is a lack of intermediate care facilities in Saskatchewan, which complicated matters when her care recipient was stubborn about entering a care home. As such, this participant was faced with the choice of unsafely leaving the care recipient in their home, or placing them in long-term care, when the level of care they needed was not quite at the point of what a long-term care facility provides.

“Living My Own Life”

The overarching category “living my own life” includes specific analyses of responses in which participants shared their struggles with maintaining their own lives due to the burden of caregiving. The participants reported there is simply not enough support from families, programs, healthcare professionals, systems (both governmental and health-specific), and communities. As well as lack of support and a lack of understanding from others in the participants’ lives contributed detrimentally to the participants’ wellbeing.

Support is Needed from Healthcare Professionals. Participants also shared that they feel as though there is not enough support from healthcare professionals in different ways. Some participants felt as though there was a lack of support because healthcare professionals, such as doctors and homecare service providers, sometimes think caregivers can handle the caring situation independently. The lack of access to homecare in both rural and urban settings was mentioned by participants. In rural settings, participants attributed the lack of homecare to their geographic location, whereas in urban settings, participants attributed the lack of homecare to staffing issues and governmental system challenges.

Support is Needed from Families. Limited support from families was a situation that troubled several participants. Participants who care for aging parents recurrently mentioned lack of support from siblings. Sometimes, it was noted that the siblings of the primary caregiver did not believe that the care recipient needed the amount of help they did. Participants cited feelings of abandonment by their families when they were left to live their caregiver experience and care for the care recipient alone. “The biggest challenge I face is the lack of understanding family and friends have of what our life is like” (Caregiver to a spouse with a neurological condition in a large urban setting). Other participants shared that they felt sad, or even angry that their families did not demonstrate compassion towards their stressful situation. Anger was especially felt when participants received criticism from their family members for the method in which care was being provided to the care recipient.
Although I am one of three children, I am the sole caregiver to my mother. I get virtually zero help, nor do I think that either of my siblings understand the extend of the responsibilities that I have.

-Caregiver to a parent with cancer and frailty in a rural setting.

I was angry with my siblings for not being there more for us. I did 99 percent of the care at home. Came to think of my siblings as narcissists. I was not trying to be a martyr as my sister once suggested. Any help was welcomed.

-Caregiver to a parent with dementia in a large urban setting.

At the time I had three babies at home. I stayed home to care for my father and children and my husband worked full time so most the housework, child rearing, cooking, and caring for my father was on me. My husband would help after he got off work, but my family would not help.

-Caregiver to a parent with a neurological disorder in a large urban setting.

**Caregivers Need to Feel Understood.** The aforementioned lack of understanding from others is a struggle reported by the participants. In addition to families not being there for support, participants reported that healthcare professionals lacked understanding as well. As mentioned previously, the lack of understanding from healthcare professionals led to more work being placed on the caregiver’s plate, including a sense of invalidation. “Nobody really understood the emotional aspect of being [a caregiver and] also a daughter and watching your parent struggle” (Caregiver to a parent with dementia in a large urban setting).

Most [care recipients are] treated as though they have dementia or like children. My mother was in [redacted facility name] but I was there providing care 6 to 7 hours per day. The day she died an aide told me I’d be missed because I did all their work. Torture for my mother and me.

-Caregiver to a parent with a heart/kidney/lung condition in a small/medium urban setting.
Respite from Caregiving. Lack of respite was a major factor that played into participants’ struggles with living their own lives. Repeated topics within the responses included never getting a break, having no backup, and not getting alone time. Participants cited feelings of wanderlust and their dreams of travelling but being unable to fulfill these dreams while in their caregiving role. “No way to go away for holidays as there is very limited respite available. We can go for a few days and family can help but not two or three weeks.” (Caregiver to a parent with a neurological disorder in a rural setting). One of the French participants in the study also stated: “Mes vacances sont utilisées pour prendre soin de mon père. [My vacations are used to take care of my father]” (Caregiver to a parent with dementia, frailty, and diabetes in a large urban setting).

Finding time to do everything that needs to be done for her. If I go somewhere even if it’s to the city for appointments, arranging for someone to check in on her can be a challenge. Planning a holiday this year with my husband and grown kids will be challenging. It’s often hard to get away for a night.

- Caregiver to a parent with a heart/kidney/lung condition and frailty in a rural setting.

A highly prevalent challenge was the inability for participants to have time to themselves, or “solo time.” When the participants reported this lack of alone time, they also made comments about how they often, if not always, have to put themselves and their self-care in second place to that of their care recipient.

I am only child and next to zero help caring for my mom before she passed away September 2020. I lived with her and also worked full time. My only resource was putting her in the government subsidized adult daycare program at the [redacted facility] here in [large urban setting] while I was at work. Only other option for a break from watching her to go out evenings or weekends was private nursing which costs $$$ per hour.

- Bereaved caregiver to a parent with dementia in a large urban setting.
I feel trapped at times. I cannot live my own life without a large amount of preparation including making sure all medications, groceries, everything to do with my mother’s house and finances are in order and that I arrange for someone to cover on call for me. My life falls in second place, and I don’t have that many good years of my own left.

-Caregiver to a parent with dementia and frailty in a rural setting.

**Lack of Freedom.** Participants also cited having no social life, loss of hobbies, and some even said they felt as though they had lost their freedom entirely. “My sister and I are with her daily. The most challenging thing is we have no freedom to have our own lives” (Caregiver to a parent with dementia in a small/medium urban setting). Participants reported that they are desperate to find a sense of balance in their life and to be able to tend to other responsibilities, such as their own homes, careers, and families. Some participants referred to this situation by saying they “feel withdrawn” from their own lives and the word “isolation” also recurred within related responses.

Finding balance. There is no balance in my life, as a full time employed mom of two, spending free time and lunch breaks at [the care recipient’s] home or at the hospital.

There are few supports for adults who need help but not fill time care. It falls to family.

-Caregiver to a parent with a heart/kidney/lung condition in a small/medium urban setting.

**Family on the Back Burner.** Being away from home to be with the care recipient was also reported to elicit feelings of isolation. Many participants who needed to spend extended amounts of time with the care recipients shared they feel as though they were putting the rest of their “family on the back burner.” Furthermore, because of the lack of respite, participants sometimes miss important life events, or seeing their own children and grandchildren growing up. One caregiver in a small/medium urban setting stated she spends “far too many hours away” from her family to care for her mother. Other caregivers talked about how they feel they always need to be there for their care recipient. “There is never a time you can step away. As a caregiver, you are emotionally, mentally, and physically always engaged with those you are providing care to.” (Caregiver to a parent with frailty in a large urban setting).
Juggling Responsibilities. Participants reported their difficulties in juggling working at their jobs and caregiving. “I found it exhausting to work full time and then monitor their medications, keep their condo clean as well as my home and prepare meals in advance for them.” (Bereaved caregiver to a parent with dementia and a heart/kidney/lung condition in a rural setting). These difficulties were felt among participants regardless of working full-time or part-time. Those who narratively reported working full-time also mentioned that getting time off work to attend to caregiving duties is often not well-accommodated by employers. Some reported even having to quit their jobs due to the demands of their caregiving role. The participants who were adult children caregiving for aging parents (also referred to as “sandwich caregivers”) reported being in an especially complex situation where they need to juggle their employment, caregiving duties, and being a parent to their own children. “Having to juggle parenting, full-time employment and elder caregiving. I don’t have much time or energy left for myself and my own needs.” (Caregiver to a parent with a heart/kidney/lung condition and cancer in a large urban setting).

Juggling work, family, mom’s medical/personal care, and trying to find time for myself. I am on call for her 24/7. I go to her place (assisted living) every morning to give meds, open blinds, and make her bed before work.

-Caregiver to a parent with dementia, a heart/kidney/lung condition, and frailty in a small/medium urban setting.

Navigating Complex Systems

Fragmented Care. Navigating the complex healthcare and governmental systems is a challenge for caregivers. Participants sometimes referred to the care received from healthcare professionals as “fragmented” or “fractured.” They reported frustrations of having to constantly repeat the care recipient’s story, including health history and the acute problem at hand to multiple professionals during the same visit. Participants recognized that the barriers to receiving healthcare in Saskatchewan are plentiful, especially with the increasing staffing issues that the province is facing. The participants noted with themselves as caregivers they feel the effects of this shortage. When the caregiving dyad finally does get access to care, the participants reported receiving little to no follow-up from their healthcare team. The lack of follow-up can complicate
matters further when there are factors such as prescription medications that may need regular assessment for appropriateness and dosing. “Fragmented care. When admitted to hospital, different attending physicians over the week who clearly didn’t look at the chart, no consistency in home care nurses, therefore continually telling ‘the story.’” (Caregiver to a parent with a heart/kidney/lung condition and cancer in a large urban setting).

We have found it a huge challenge getting the medical and psychological help our mother needs. We feel like it’s up to us to decide on how much medication to give her and when we finally did get some help, we can't get any follow up to see how things are going.

- Caregiver to a parent with dementia in a large urban setting.

**Healthcare Professionals Need to Respect Caregivers.** Some participants noted the lack of respect they received from healthcare professionals when they accessed care. They reported that there can be ageist attitudes expressed by healthcare professionals, which they sometimes attribute to inadequate training in providing geriatric care. The ageism included aspects such as not treating care recipients with respect or dignity and acting as though care recipients are incapable of making decisions for themselves. Participants also noted that they feel rushed or dismissed when accessing healthcare services, as if the information they offer was invalid and unimportant. “Trying to get the medical community to take his health seriously and constant dismissal of information I give them to address the health issue.” (Caregiver to a parent with a heart/kidney/lung condition and cancer in a rural setting).

Having to deal with a fractured health care system and people treating Mom as if she's a child. Her body may be giving out on her, but her mind is very sharp. It's hard to not lash out at them when this happens.

- Caregiver to a parent with a heart/kidney/lung condition, vision deficits, and diabetes in a large urban setting.

A common frustration felt by participants is that the dyad of care recipient and caregiver are not acknowledged as a partnership by healthcare professionals. Participants reported feeling
that if they had this acknowledgment, navigation of the healthcare system may be better facilitated.

Being the supporter at doctor appointments. More gets accomplished or acknowledged if you, the caregiver, is present which is frustrating since my parent is very capable of communicating their needs themselves. I often have to indicate I’m present for support and [to be the] driver but will express my concerns if I feel there is a need.

-Caregiver to a parent living with a heart/kidney/lung condition in a rural setting.

Availability and Accessibility of Resources. The lack of available resources or knowing where to go for resources was a challenge reported by the participants. They shared that it is hard to access long-term care, but also hard to know when to make the decision to place the care recipient in care due to not receiving adequate support and navigation assistance. Furthermore, the participants feel as though the Saskatchewan healthcare system is not oriented to older adults aging in place. One caregiver in a large urban setting stated that the “system is not set up for our aging population.” Difficulties accessing services such as mobile phlebotomy, telehealth, and supplies and equipment for mobility make caregiving even more challenging. Participants recognized that the lack of access to services has also been exacerbated by the COVID-19 pandemic, which shut down many community health programs. Transportation creates a significant barrier as well when care recipients need assistance in getting to appointments, which especially affects rural residents when they need to travel to cities for access to specialists and allied health professionals such as physical or occupational therapy.

Healthcare System Not up to Par. Many participants report feeling unhappy with Saskatchewan’s healthcare system. They have a lack of trust in the system, feeling that it’s not looking out for them. “Saskatchewan’s broken health care system. It’s driven by budgets and not client-centred at all despite claims from the Sask government.” (Caregiver to a parent with dementia and cancer in a large urban setting). Some participants reported that there was simply “too much red tape” to accessing much needed support. These frustrations circle back to participants feeling helpless and overwhelmed. One participant shared that the system is not really there to help those in need of care until something acute or “catastrophic” occurs as they described the down-stream approach the Saskatchewan system takes.
The complete lack of community support, inconsistent care that had already been arranged, the willingness for people to live at risk due to being “difficult” due to their dementia, the difficulty accessing long term care and the idea that something catastrophic has to happen for the system to engage, the fact that people require money to get help.

-Caregiver to a parent with dementia in a large urban setting.

**The Expensive Price Tag on Caregiving.** Expenses related to caregiving complicate matters further, when participants reported that the current systems offer limited funding, if any. Examples of financial costs that participants incur through their role include household cleaning, preparing meals, transportation (especially when rural with the cost of gas to get into the cities), renovations to enhance living spaces for mobility, homecare, assisted living, and many more. These costs are all incurred, and many participants reported having to take time away from work or even quit their jobs, which results in their loss of income. “Money. I am low income and so I don’t have any money to pay for what is needed for outside [caregiving tasks] … [I have to] fight for myself.” (Caregiver to a parent with dementia in a rural setting). In addition to these complications, participants reported that lack of tax breaks or government grants for caregivers currently exist in Saskatchewan. “Lack of programs, support, and respite care for caregivers. Very limited tax breaks for caregivers. It costs a lot of money as well as most requiring care have a limited income.” (Caregiver to a parent with dementia in a rural setting). Adult children acting as caregivers to their aging parents may also have children of their own, which adds to the lengthy list of expenses. “Financial difficulties, if there was funding available for adult children to care for their aging parents, it would relieve a lot of the stress.” (Caregiver to a parent with dementia in a rural setting).

The whole system ignores dementia sufferers and there is no one who cares that will help in any way with the care they need!! Home care is expensive … $3000 for 6 months and I had to quit my job to care for my dad for free because family is not entitled to any benefits to care for a loved one.

-Caregiver to a parent with dementia in a small/medium urban setting.
**Accessing Systems While Caregiving Rurally.** In rural Saskatchewan, with increasing closures of healthcare facilities and rural hospitals, participants report they are becoming frustrated. The rural participants shared they often must travel with the care recipient to large urban centres to receive care, which can also be disorienting to the care recipient to be out of their regular environment. As well, rural healthcare facilities often have limited hours.

[The] Saskatchewan health care system is the most challenging. Although we have a hospital, it is emergency care Monday-Friday 8:00 am - 5 pm. After 5 or weekend if care is needed the only option is ambulance to another community.

- Caregiver to a friend or neighbour with dementia in a rural setting.

Almost non-existent home care services, lack of intermediate care facilities and handicap transportation in rural communities. Declining medical facilities in rural Sask. Elderly must now travel for basic ER care. Admission is often in a hospital that is an hour or more away from home. Several transfers to different facilities. Long distance for rural patients to travel for specialist care and expense. Lack of medical training for average family care provider.

- Caregiver to a parent with a heart/kidney/lung condition, cancer, and diabetes in a rural setting.

Rural participants reported other unique challenges related to rurality. As demonstrated in previous quotes, participants in rural settings are challenged with the expenses of their caregiving role. Furthermore, participants whose care recipients required advanced care needed to relocate to larger unfamiliar centres and incur the costs of moving as well.

Lack of home care services in rural resulting in those that require care needing to be relocated to larger unfamiliar locations. No support to have a parent move in with family due to lack of staff in rural. Childcare costs are 35-45 dollars a day but to hire a private care provider for older adults is 36/hr.

- Caregiver to a parent with dementia in a rural setting.
Participants in northern communities also reported there was an entire absence of care homes in their areas, meaning they had no respite services at all. “[Lack of] support systems, respite care, getting to specialist appointments, financial aspect of maintaining a home and bills while caring for your loved one in a northern community with no respite or care homes.” (Caregiver to a parent with a heart/kidney/lung condition and frailty in a rural setting). Moreover, participants noted the issue of the healthcare system not being oriented to older adults aging in place, which was especially felt amongst rural participants.

We were able to hire a private caregiver to assist my siblings and I to look after mom. Rural home care is much less available than in urban centers and we were able to obtain approximately 1 hour of assistance per week to help with required 24/7 care. The system is designed for sick and elderly to be placed into care facilities rather than being cared for in their own homes. Care at home would be a lesser drain on the system financially. Accessing care through emergency rooms also needs to change. Many issues do not require emergency medicine, exposure to long wait times, viruses, and infections. Access to a health care provider virtually from a home environment would be helpful. As it currently designed, the system funnels all patients, regardless of circumstance through the emergency room and into facilities including palliative care patients. Patients do better physically and emotionally in their own home environment.

- Caregiver to a parent with cancer in a rural setting.

“Am I Doing it Right?”

This overarching category encompasses how caregivers often reported a lack of confidence in their role, especially when it came to decision making. Participants made comments towards the concept of “winging it” in their role. “Worrying [if] I am able to deal with everything that happens!! And being able to assist as much as possible.” (Caregiver to a spouse with dementia, frailty, vision deficits, and diabetes in a small/medium urban setting). Another participant shared: “Knowing what to say, how to react, and of course helping parent with ‘private’ care (bathing, toileting, etc.), feeling like you may be ‘losing your mind.”” (Caregiver to a parent with dementia in a rural setting). As such, feelings of guilt and inadequacy were tied to
these responses. “Feeling of guilt, hoping that I'm doing a good job, and wishing for more support” (Caregiver to a parent with dementia and cancer in a rural setting).

**Going it Alone.** Some participants felt inadequate when they were facing their caregiver experience alone, or without sufficient help. “Being the lone engaged family member, making it up as I go along, having to set boundaries with care recipients in order not to completely lose myself.” (Caregiver to a parent with dementia and a heart/kidney/lung condition in a large urban setting). Participants reported having to take the care recipient into consideration with making any decision, whether it was for the care recipient or themselves. Family dynamics sometimes complicate the caregiver experience, when other family members do not agree with the decisions that are being made by the primary caregiver. “Time demands and expectation that I’m available immediately at all times. Criticism from siblings for being there too much or how things are being done.” (Caregiver to a parent with a heart/kidney/lung condition and cancer in a rural setting).

**Weight on the Shoulders of Caregivers.** An incredible amount of responsibility was shared to fall on the participants when they are in their caregiving role. “Lack of knowledge about resources available to help her… Being her sole caregiver has been a heavy load.” (Caregiver to a parent with vision deficits and mental illness in a large urban setting). It can be difficult to find help, making it difficult to leave the care recipient alone for even short periods of time. “Finding people who understand and can help when I’m overwhelmed or scared or just needing space.” (Caregiver to a parent with dementia in a large urban setting). Moreover, participants stated it can be difficult to ask for help. As mentioned in a previous category, sometimes the help caregivers require is just need an ear to listen, as the caregiver experience can be lonely. One caregiver to a spouse with a neurological disorder in a rural setting wrote in their response “It really is lonely. Being responsible for everything is really hard.” Not having easy access to information or orientation to the caregiving role creates challenges as well.

Finding support services that are easy to access and on-going. It took me 25 years to find an adult day program for my special needs brother. Also took 25 years to find the private care service home through social services. Despite his being a social services client, his workers never told us anything about these programs. Always have dig for info and fight
hard to get what you want. Policies are often outdated and ask for information that is unavailable.

-Caregiver to a sibling with an acquired injury, diabetes, and cancer in a large urban setting.

Harnessing Strength. Ultimately, participants reported finding themselves having to harness emotional and physical strength to face their challenges. Participants shared it takes much patience to be a caregiver, especially when forging on their caregiving journey alone. “The dementia journey is long with an unpredictable path. Sheer stamina and my own endurance for the journey was very challenging. Frankly, it’s likely a good thing I didn’t realize how long it would go on.” (Caregiver to a parent with dementia and a heart/kidney/lung condition in a small/medium urban setting). The challenges associated with caring for an individual with dementia were mentioned on several different occasions. “Not being able to take a break during crisis periods of illness, hospitalization, etc. as I’m the only one who can anticipate her swings in and out of dementia and communicate effectively with her.” (Caregiver to a parent with dementia in a small/medium urban setting).

Fearing the Unknown. Lastly, the uncertainty of what is to come in the future and fearing the unknown is another challenge that caregivers experience. One spousal caregiver in a large urban setting noted that their spouse has Parkinson’s disease, and since it is a progressive disorder, they “get depressed thinking about what the future will be like.” With so much time and effort invested into their caregiving role, some participants wondered what they will do when their caregiver eventually dies. Uncertainty associated with these thoughts is troubling and can take a toll on a caregiver’s mental wellness.

Caregiving at a Distance

Caregiving at a distance, although a smaller category, seemed to be significant in the context of Saskatchewan caregivers due to the broad geographic distribution of persons within the province. “I have to drive 4 hours to see my mom and I go once or twice a month. It is time and money consuming.” (Caregiver to a parent with dementia, a heart/kidney/lung condition, and frailty [caregiver lives in a rural setting]). Regardless of the amount of distance between the caregiver and care recipient, participants reported distance to be a significant challenge. “Sometimes I am not able to make the three-hour drive to take care of him and getting someone
to come in from home care is painful.” (Caregiver to a friend with frailty [caregiver lives in a small/medium urban setting]).

**Barriers Related to Distance.** Distance proved to be a barrier in different circumstances. For example, travel time to get to the care recipient was a barrier to being there for them, and also was reported to be a concern during the long Saskatchewan winters. Moreover, participants with careers reported struggling to get extended amounts of time off work to travel and be with the care recipient. “We share the roll with 3 other siblings to my in-laws. Not being in the same city and having to take a week off work a month to provide care is tough.” (Caregiver to a parent with dementia [caregiver lives in a large urban setting]). Of final note, the aforementioned juggling of work, family, and caregiving is complicated even further when caregiving at a distance. Distance also seemed to be a contributor to further feelings of guilt, when participants had to juggle their time between locations and felt they were not meeting anyone’s needs.

Trying to meet my dad’s needs and being his main source of emotional support while living in another community and trying to take care of my other family members while working. I constantly feel guilty about not doing enough to meet anyone’s needs, and I also feel guilty if I take any time for myself.

-Caregiver to a parent with dementia, frailty, and mental illness (caregiver lives in a large urban setting).

**Question 2: Positive Aspects of Caregiving**

The second survey question asked participants: “What do you find is positive about your caregiving role?” The categories that were developed from codes were: (1) caregiving is rewarding; (2) having the ability and opportunity to care; (3) ensuring quality care for the care recipient; (4) personal growth through being a caregiver; and (5) caregiving is *not* a positive experience.

**Caregiving is Rewarding**

**Treasured Time.** Despite facing several challenges, participants had a significant amount to say about how rewarding their caregiver experience can be. One of the most reported positive aspects of the caregiver experience was getting to spend time with the care recipient. Participants also reported feelings of devastation and loneliness when they were no longer able to
spend time with the care recipient in the same capacity. “He is the love of my life, married for 52 years this July, I was glad to do all I could for him, I cried lots when I had to place him in long term care.” (Caregiver to a spouse with dementia in a rural setting).

I enjoy the opportunity to spend time with my mom in what I realize are the last years of her life - there are emotional gifts that come with sharing this time with her, on a daily basis - putting old hurts to rest and coming to a place of peace with her.

-Caregiver to a parent with vision deficits and mental illness in a large urban setting.

**Learning the Care Recipient’s Story.** Treasuring time with the care recipient included making new memories with the care recipient and learning the care recipient’s life story. Participants who were able to learn more about the care recipient’s past reported that this was the most special part about their caregiver experience. “Grateful I still have my parent in this life. She has the best stories to tell about our family. Things I didn’t realize happened. Lots of good memories are shared.” (Caregiver to a parent who needs more support in older age in a large urban setting). For adult children who are caregivers to their parent(s), getting to know their parent as an adult allows for the development of new relationship dynamics and facilitates relationship building. One caregiver to a parent with dementia in an urban large setting stated that the positive aspect of their caregiver experience was “hearing the occasional story I did not know before.”

The learning of the care recipient’s story sometimes expanded to sharing traditions and family recipes. “The fact I get to spend time with my parent. Our family is a village. We look after each other. Shared wisdom, stories, recipes, handing down family traditions to new generations.” (Caregiver to a parent with frailty in a large urban setting). Through spending time with one another and learning more about each other, new memories are forged in the caregiving exchange. Participants described the creation of new memories as a deepening of their relationship with the care recipient, with one participant stating how special it is to be in the caregiving exchange where “more treasurable memories [are] accrued.”

**Family and Togetherness.** The concept of staying together was also a positive aspect of being a caregiver. Participants referenced the values they hold regarding the importance of
family. More time together allows for the sharing of new experiences, such as grandparents getting to know their grandchildren in closer proximity. Staying together also sometimes meant being together to share time with each other at the end of the care recipient’s life, which was especially fulfilling for participants when their care recipients had wishes such as dying at home.

**Enhancing the Wellbeing of the Care Recipient.** The idea of “facilitating happiness” and “giving the care recipient their best days” was brought about by participants. “The richness of the small moments. Reading to him and seeing that spark of humour. The knowledge that we are all doing are best and that he is not alone.” (Caregiver to a parent with frailty in a large urban setting). Participants reported a positive aspect being when they know they have done their best for their care recipient, which was validated through small gestures such as “seeing the smile on their face.” Giving the care recipient the best quality of life possible is an important aspect but caregivers feel rewarded knowing they are working towards providing a quality of life to the care recipients. Caregivers also feel rewarded knowing that they are keeping the care recipient safe in their care.

**Sentimental Caregiving.** Love, appreciation, and dedication were three sentiments reported by participants to be positive aspects and motivators to the caregiving role. “I formed a close loving bond with both of them after years of them thinking of me as ‘only’ a daughter-in-law.” (Caregiver to a parent with dementia and a heart/kidney/lung condition in a rural setting). Providing loving care to the care recipients helped participants find strength, faith, and sometimes forgiveness in relationships that were strained in the past. Some participants reported caregiving to be an honour and a privilege, with statements such as “It is a blessing to walk your parent through old age” and “I’d do it again in a heartbeat.” Other participants mentioned the sense of purpose they derived from their caregiving role.

Feeling satisfied that I was able to provide excellent care for my mom and not some other person who doesn’t have a personal relationship. Caring for my mom gave me a sense of purpose, and I felt it was an honour and privilege to take care of her.

-Caregiver to a parent with a heart/kidney/lung condition in a rural setting.

**Catching the Good Days.** Lastly, getting to observe the positive moments and appreciate moments of health were special to the participants and positive aspects of the caregiving role. “I
get the honour of being there for her lucid times and provide the LOVING care she requires.” (Caregiver to a parent with dementia in a small/medium urban setting). “Celebrating small wins” was a sentiment felt in cases of good health. For participants who are caregivers to older adults with dementia, moments of lucidity were reported to be special to them. “The times where you can see their moments of enjoyment and a glimpse of who they once were. And the opportunity to show them that they are still an important part of your life.” (Caregiver to a parent with dementia in a small/medium urban setting).

**Having the Ability and Opportunity to Care**

**Feeling Fortunate to be a Caregiver.** Participants reported appreciating having the ability and opportunity to care for the care recipient. It allows them to feel helpful by improving the care recipient’s quality of life, taking on the caregiving burden to protect others, or being there for the care recipient when no one else will or can be. “I was there for them, and they needed help.” (Bereaved caregiver to a parent with cancer in a rural setting). One participant wrote about taking on the role of caregiving to protect their adult children: “I like helping others and I feel as though I am also supporting our children who would have to do some of this.” (Caregiver to a spouse with diabetes and arthritis in a small/medium urban setting).

**Independence and Quality of Life.** Improving the care recipient’s quality of life involved supporting their independence and self-efficiency, as well as instilling a sense of safety for them and fulfilling their wishes. Being able to support independence in the face of health, mobility, and cognitive challenges gave participants a sense of a job well done.

Protecting elders from exposure to humiliating downsides of their decline, boosting their sense of relative autonomy and independence, working with what’s left to celebrate and expand into, overlooking their understandable frustrations, and dealing with their sadness over inevitable losses, avoiding pitfalls of family expectations over performance at family events, shielding your parents from grim realities (as they did for their kids), recreating opportunities to revive memories faltering, then letting all that go to create something new and different, going with their flow…

- Caregiver to a parent with dementia, a heart/kidney/lung condition, and cancer in a small/medium urban setting.
By supporting the care recipient in their home, caregivers facilitate maintaining normalcy in the care recipient’s day-to-day lives. Continuing with “business as usual” as able was a value shared by participants. Participants were reported being proud to provide a quality of life to the care recipient, most notably when it involves keeping the care recipient at home. This was echoed in both urban and rural settings: “The positive side to this role is keeping my mother safe and [fulfilling] her wish to stay in her home.” (Caregiver to a parent with a heart/kidney/lung condition in a small/medium urban setting). “The opportunity to keep my mom at home in her own place which she’s so dearly loved and wanted to do.” (Caregiver to a parent with dementia in a rural setting).

**Ensuring the Care Recipient Feels Safe.** Participants also reported feeling relieved and happy when the care recipients have a sense of security under their care. Moreover, care recipients often want to stay in their own homes to age in place. Having the ability and opportunity to keep the care recipient in their home creates positivity in the caring relationship.

Enjoying the moments that are meaningful to them all. When they laugh and smile and feel good and safe. When they say thank you from their hearts not because I need to hear it but because they are grateful. I’m happy they are safe with us.

-Caregiver to a parent with a heart/kidney/lung condition and post-stroke in a small/medium urban setting.

**Giving Back to the Care Recipient.** The idea of reciprocity and “giving back” to the care recipient was another notable concept within the participants’ responses. In the cases of adult children providing care to their aging parents, the idea of modelling the value of caregiving for their own children was mentioned as well. “Looking back, the time I got to spend with my parents. I hope I showed my own children the importance of care and empathy.” (Caregiver to a parent with dementia and a heart/kidney/lung condition in a rural setting). Another participant stated, “We get to show our kids how we want to be treated when it’s their turn.” (Caregiver to a parent with dementia in a rural setting).

Some participants who are caregivers to parents referred to the caregiving exchange as being a “role reversal,” where they noted that they get to provide care to their parents just as their parents had provided care to them when they were children. Other participants wrote about how
when you care about someone, taking on the caregiving role feels like “doing the right thing.” A participant in a rural setting referred to caregiving as a “duty of love” when discussing caring for their parent with cancer: “I feel it is a ‘duty’ of love, of life itself to show compassion for oneself and one’s parents, that it is the price of living a good life to try to do the right thing.”

I gave him the best quality of life that I could give him. Having him home taught my children compassion. Caring for my father motivated me to become a nurse and my career is caring for the elderly in long term care.

-Caregiver to a parent with a neurological disorder in a large urban setting.

Access to Respite Facilitates Caregiving. Lastly, having access to support and respite (services) facilitated the participants’ ability to provide care, which added to the positive aspects of caregiving. Proximity to services, quality care from healthcare professionals, and feeling the support from others and their communities are factors that contributed to positive aspects of caregiving. Within the responses, it was resonant how participants feel grounded when they are being heard and understood. One caregiver to a parent with dementia and a heart/kidney/lung condition in a rural setting stated that they feel positive about their caregiving role “when people actually listen to what we need.”

Ensuring Quality Care for the Care Recipient

Being in the Know. This category involved concepts such as being fully aware of the care recipient’s situation, knowing the care recipient is safe, and having the ability to provide comfort through companionship, symptom management, and spirituality. Some caregivers reported that the care recipient used to not disclose their health and wellness status, so having the care recipient in closer proximity allowed these caregivers to have awareness of what was going on in the care recipient’s life. “Knowing that I helped mom as much as I possibly could to ensure her to have some quality of life. Also, with seeing her daily I can see how she really is managing.” (Caregiver to a parent with dementia, a heart/kidney/lung condition, and mental illness in a small/medium urban setting).
Not having to worry about how they are doing because they are seen every day. Not having to travel to pick them up for appointments. Wondering if they're really ok not just what they tell you because they "don't want to be a bother."

-Caregiver to a parent with a heart/kidney/lung condition and diabetes in a rural setting.

**Ensuring Safety.** Safety and knowing the care recipient is receiving the care that they need, whether from the caregiver directly or being in a good care home, was another positive aspect reported by participants. For the participants who were able to keep the care recipient in their own home during the COVID-19 pandemic, there was a sense of relief and satisfaction in knowing they were safe and secure, with special consideration regarding the visitor restrictions that were put in place in long term care homes. One caregiver to a parent with cancer in a rural setting stated, “There is great satisfaction knowing that no COVID or long-term care hell was perpetrated on my loved one.” Many other participants made similar statements to the effect of knowing that they can provide better and more personal care than a long-term care home. Another caregiver to a parent with cancer in a rural setting reported the positive aspect of being able to protect the care recipient “from outside elements that attempt to take advantage of the elderly.” These notions were coded in the content analysis as “live-in care recipient = less worries.”

**Providing Comfort.** Being able to provide comfort is an important positive aspect of caregiving. One participant who was also a nurse reported that their nursing experience facilitated them being able to provide comfort and symptom management. Other participants cited that they incorporate spirituality into their provision of care to give encouragement to the care recipient.

Ensuring my elderly stepmom, sister and brother have all their health care needs respected, heard at least by me, treated so they can live their lives comfortably, pain free as possible, infections treated. It makes me happy when they're happy and comfortable. I'm glad I know medical pathways from my many years of nursing.
- Caregiver to a parent and siblings with a neurological disorder, heart/kidney/lung condition, cancer, and arthritis in a small/medium urban setting (unable to discern the specific conditions of each care recipient).

**Advocacy.** The final positive aspect that was reported within this sub-category was the participants’ ability to be an advocate for the care recipient. A caregiver to a parent with a heart/kidney/lung condition in a rural setting mentioned that this ability was enhanced by “understanding their needs so they aren’t ignored by medical professionals.” Assisting the care recipient in navigating the complex Saskatchewan healthcare system takes patience and perseverance and participants reported appreciating knowing that they are doing their best to advocate for the care recipient to receive appropriate care.

**Personal Growth Through Being a Caregiver**

**Self-Validation and Doing Your Best.** This category had some overlap with previous categories. However, what made this sub-category unique and relevant was that caregiver participants made direct comments towards their personal growth through being a caregiver. Participants cited the self-validation they felt through knowing they are doing their best, which included celebrating small successes and feeling good about the commitment they were making to the care recipient or family in general. Making a difference and giving the care recipient a sense of dignity also allowed participants to grow as individuals and learn more about themselves and their strength and resilience.

It was a privilege to care for my parents and I came to know and appreciate them in different ways in the last years of their lives. I also learned that we are all the same in how our bodies work and that there is dignity in that. To care for and do what was needed with great care and respect.

-Bereaved caregiver to parents with heart/kidney/lung conditions and vision deficits in a small/medium urban setting.

I love my parents and would do it again for my dad in a heartbeat (he passed away) and I will continue to help my mom. I also want to help others in my community live out their last days with dignity and have someone care about them.
Caregiving is not a Positive Experience

While the purpose of this survey question was to determine what participants found was positive about being a caregiver, some participants said that caregiving is not a positive experience. Repeated phrases from these participants included “nothing” and “not much.” One participant expressed this in more detail: “Not a thing!! We love our dad but it’s hard and stressful and never-ending chaos with no help or support from any health care in this area!!” (Caregiver to a parent with dementia and a heart/kidney/lung condition in a small/medium urban setting).

Digging Deeper. Most of the participants who felt negatively about their caregiving role gave only a few words to state that their caregiving experience is solely negative, but some participants started by saying “nothing” but dug deeper and reflected on what might actually be a positive aspect of their caregiving role. These responses included: (1) “Not a whole lot for me, I guess that my mother can stay in her own home.” (Caregiver to a parent with dementia and frailty in a rural setting). (2) “Not much, honestly. Just knowing that she is safe and getting the care she needs.” (Caregiver to a parent with dementia in a small/medium urban setting). (3) “Not much. I guess I’m glad he’s getting help at the moment, from someone. It happens to be me right now.” (Caregiver to a spouse with dementia in a small/medium urban setting).

It Could be Worse. “It could be worse” is a reflection from a caregiver to a spouse living with dementia in a large urban setting stated that the care recipient “has not reached a violent stage yet.” Other caregivers stated it was difficult to think of how to answer this survey question but reflected on their emotions towards the care recipient. “That is difficult to answer other than to say I loved her, and I am willing to care for her when she no longer can care for herself.” (Caregiver to a spouse with dementia in a large urban setting).

Question 3: Support Priorities of Caregivers

The third survey question asked participants: “What do you think is most important for support in your caregiving role? In other words, what are your top priorities for support?” The overarching categories, which are referred to as the support priorities themselves, were: (1) “help when we need it!”; (2) an ear to listen and a shoulder to lean on; (3) optimizing the care
recipient’s health; (4) healthcare professionals that care; and (5) improved policies, legislations, and regulations.

“Help When We Need It!”

More Support Services Required. “Help when we need it” was the category developed with the largest number of references. Help requested included access to homecare, long-term care, information, assistance with daily tasks, and more resources in general. Many participants responded that there are simply not enough services in Saskatchewan to assist them in their caregiving role. Some called for better coordination of the services that do exist. “When I reached out for help and support, I felt like I had to get upset and beg for help and resources to help me with my parent etc.” (Caregiver to a parent with cancer in a small/medium urban setting).

I wish there were a more coordinated approach to senior, assisted-living, housing in [large urban setting]. Currently, CPAS (Client/Patient Access Services) gives you a list and you need to call each place separately to find out what they offer, cost, and wait lists. It would be most helpful to have a centralized placement office that coordinated the needs.

-Caregiver to an older adult with dementia in a large urban setting (relationship undisclosed).

We have a day program in our community. They picked mom up daily and she went to “work.” She moved in with us at the age of 89 after having sat under [sic] in a hospital waiting room for almost a year... No programming for her as she wasn’t in long term. Moving her here and having a reason to get up every day and go to a lively program. Priceless! Finding a physician to care for her. Getting respite when I needed it. I didn’t use it often and maybe I should have. Kinda felt guilty about it.

-Caregiver to a parent with a heart/kidney/lung condition and post-stroke in a small/medium urban setting.

Access to Homecare. It became clear that access to homecare is something many Saskatchewan caregivers struggle with. Rural participants note that homecare is often only
available in urban centres and that “rural people are forgotten.” The costs of homecare were a barrier to receiving help, as many participants reported needing to hire private aides to help them in their caregiving role. Participants also said that homecare cannot come visit often enough, leaving much of the work remaining for the caregiver. “The most frustrating part is care home workers being inefficient, not trained and not doing all aspects of parents care on a timely and regular basis without being reminded or follow ups.” (Caregiver to a parent with dementia in a small/medium urban setting). Lack of consistency in homecare providers leads to caregivers having less trust in homecare services. Also, the homecare providers do not have a full understanding of the care recipient’s condition(s). “Consistency. The home care nurses are seldom the same. They don't know what has happened the previous visit. Every visit feels like starting over with the care.” (Caregiver to a parent with cancer in a small/medium urban setting).

Home care needs to be revamped. Daily in home supports are needed. Meals on wheels 7 days a week more than one meal per day. Med assistance for every dose. Home care needs to have scheduled times for arrival not hours long windows for arrival, so clients are more compliant with using services.

- Caregiver to a parent with dementia and a heart/kidney/lung condition in a rural setting.

Access to Quality Care in Care. “In care” refers to individuals receiving care in long-term care and assisted living settings. Access to long-term care was reported to be essential with Saskatchewan’s aging population. Participants recognized that as older adults age with their spouses, ensuring togetherness between spouses in care homes is critical to maintaining their wellbeing.

In our case, it was keeping my folks together in the same facility. Whatever level of care was needed for each of them, they were both aware of each other and needed to be together. After Dad passed, it was being able to have Mom in the local LTC, so I was able to take on outings and look out for her while she was a resident.

- Caregiver to parents with dementia and a heart/kidney/lung condition in a rural setting.
**Disappointed in Care Delivery.** Participants reported feeling disappointed in the care the care recipient received in some facilities, which was related to them feeling as though there was no help available. They called for expansion of services provided in care homes, as well as fair and equitable placement for the care recipient via a smoother admission process. One participant in a large urban setting noted that it took the care recipient 10 months to find placement in a care home, and in the meantime, the caregiver reported having a “breakdown.” Others reported the similar sentiment, saying it is too difficult to qualify for appropriate nursing care.

Medical support. The doctors are very supportive and recommend nursing home care, but we get shot down for nursing care because the nurses that deal with placement in nursing homes say she is not sick enough. She doesn't know where she is and who she is, doesn't recognize people or places, but that's ok because the nurses say so. Screw the caregivers.

- Caregiver to a parent and sibling with dementia and a heart/kidney/lung condition in a rural setting.

**Safety in Care is a Concern.** Participants reported wanting to know that the care recipient is safe while in care. Access to this assurance became especially difficult with visitor restrictions during the COVID-19 pandemic, when family caregivers were unable to visit the care recipients in care. As well, some participants reported that there is not enough nursing observation in long-term care. They report that they would feel more comfortable with regular checks of vital signs, medication assessments, and mental wellbeing. Caregivers to older adults with dementia wished that staff in care homes had better training on how to provide care to this population.

To make sure they are safe. It is also very important to watch their emotional health. Covid lockdowns were killers of seniors. I assist with minor things (taking to appointments, visiting etc.) for several other family and community seniors and I saw so much deteriorating during the restrictions, I also seen some of those people give up. They didn’t feel life was living if they couldn’t have visitors or do anything.

- Caregiver to a parent with dementia in a rural setting.
I found the following in private care homes and in government run long term care facilities:
- staff who understand condition of dementia.
- staff who listen to caregiver who knows the care recipient.
- staff who remember care recipient is a person & not treated like a child. My father was told at one time by an aide that they would cut his tongue out.
- staff who listen to care recipient & not dismiss their concerns.
- caregiver is notified with changes of condition, injuries, changes in care needs of care recipient
- staff who understand palliative care & how to best care for a dying care recipient.
- aides are able to provide basic care but are not qualified to assess and decide care needs.

- Caregiver to a parent with dementia and a heart/kidney/lung condition in a large urban setting.

**Day-to-Day Life in the Community.** Outside of long-term care, participants reported needing more help with daily tasks in the community. These daily caregiving tasks included activities of daily living (ADLs) such as receiving adequate nutrition and personal hygiene care, and instrumental activities of daily living (IADLs) such as grocery shopping, banking, and housekeeping. Other tasks that participants noted needing more help with included blood glucose monitoring, medication administration, wound management, blood pressure management, filling out forms and paperwork, meal preparations, scheduling appointments for multiple specialists, and transportation. “Ensuring that she is well fed, well dressed, and kept clean. After those basics are met, ensuring that she is stimulated and feeling that she is a part of the house.” (Caregiver to a spouse with dementia in a large urban setting).

Providing enough support that allows them to live independently; ensuring they are comfortable in their living space; can easily access essential needs - independent shopping, medical appointments & social circle (i.e., church, friends); finding outside supports such as weekly housecleaning. Ensuring driving skills are adequate to be safe

- Caregiver to a parent with a heart/kidney/lung condition in a rural setting.
Ensuring medications, food, financial and everything about her house is in order. I would really like if there was an organization, I could go to who would provide daily home care to my mother. Currently there is twice a week home care visits to help with personal care and house cleaning. But during the first several months of COVID 19, that stopped, and it all fell on me.

- Caregiver to a parent with dementia and frailty in a rural setting.

**Physical Strain and Injury.** Due to the physical strain of the caregiving role, sometimes caregivers can end up with injuries and back problems. “Support for caregivers. At one point I could not walk for a month or so much for a couple more months due to back issues. We could not get help outside of family for small chores, food prep and cleaning and transportation.” (Caregiver to a spouse with cancer in a small/medium urban setting). One participant noted that although they did not have back problems yet, it was a concern of theirs when providing continuous physical care to the care recipient.

It would be helpful if there were people that could come into the home and help, with things the caregiver cannot do. For example, while I was looking after my husband, I got a severe back issue that made it impossible for me to do anything for a month. Covid contributed to a lot of the issues but there is not a place in my city to call for help with rising something or some laundry service or cleaning I know in [large urban setting] there are such services but nothing here.

- Caregiver to a spouse with cancer in a small/medium urban setting.

**Information Needs.** When caregivers need information, they want to be able to access it freely and easily. Participants noted the lack of a central place or person for information within the province. They called for better signposting and advertisements for resources as well. This navigation assistance and wayfinding for support was mentioned several times throughout responses but participants also wanted to know they could trust the information they were receiving.
Knowing who to ask for help and having access to that resource on a consistent basis as well as having the contact be the same individual over time rather than a difference person every few days. Very frustrating.

- Caregiver to a parent with cancer, frailty, and vision deficits in a large urban setting.

An easy way to find support. For me it’s not about being able to jump on the phone or go to meetings. Sometimes I’m trapped at home with my loved one who refuses at times to acknowledge their condition and I need help. Online communication or support would be great as I could reach out when I need it without announcing the issues out with her present and allows me to communicate when I can’t leave her alone.

- Caregiver to a in a large urban setting.

Finding resources for them and knowing how to navigate the systems. Being brave enough to stand up to authorities when being treated unfairly! Always digging for what is needed. Haven’t found anything easy! The GEM [Geriatric Evaluation and Management] program is exceptional but hard to get info about!

- Caregiver to a in a large urban setting.

**Understanding the Care Recipient’s Medical Condition.** In addition to assistance in navigating complex systems, participants wanted to be able to understand what was going on with the care recipient’s medical conditions. They want to understand the conditions themselves but also receive updates on current health statuses, learn how to manage symptoms, and make appropriate decisions for the care recipients.

Allowing support people to attend medical appointments and have access to information shared with the patient so they can have understanding and clarity regarding their health and treatment options.

- Caregiver to a parent with a heart/kidney/lung condition and cancer in a small/medium urban setting.
**Transportation as a Barrier.** As usual, rural participants reported sometimes struggling with finding assistance from any service altogether. Rural participants also noted the barrier of transportation in their responses to this survey question, describing needing to travel long distances to receive the help they and the care recipient need. The financial cost of travelling and other rural expenses was also mentioned.

We live in a small town with no pharmacy, doctor, or care facility. When my mom was in hospital and, later, my dad in care, the number of miles I put on was horrendous. There is no one to call here and every health challenge had to be dealt with an hour away.

- Caregiver to a parent with dementia and a heart/kidney/lung condition in a rural setting.

Rural support for those who live in rural. I will need to sell my home and move to city as my sister's condition worsens as there is zero support in rural SK. Cost of living in the city is at least three times what it is in the rural.

- Caregiver to a sibling with dementia in a rural setting.

**Need for Respite.** Respite is crucial to caregivers being able to take care of their own health. Day programs for care recipients are few and far between, but appreciated when they exist. Participants reported sometimes bringing the care recipient to the hospital to be admitted in order to receive some respite for the feelings of burden they may be experiencing.

Respite care is very limited if it is available at all. I don’t know what else there could be. I would like to see more set up in this area. Putting them in the hospital should NOT be the answer. This is not where they should be - taking up acute care beds. The families don’t want them there, the staff is not wild about them being there holding acute care beds for indeterminate lengths of time. Expensive as well. I’d also like to see respite care set up for parents and caregivers of children and adults with special needs such as Autism. This province also needs to consider more hospices for those who are in need of care at end of life from illness/ cancer. Again here, the hospital should not be the place available outside of the home.
-Caregiver to a spouse with a neurological disorder and post-stroke in a rural setting.

Respite, counselling for families dealing with an elderly person who does not see need for service and is making poor choices in lifestyle due to declining cognition, a trained person to assist families with decisions about care needs and helping elderly see the necessity of supportive care and inevitable life changes. Many caregivers are themselves senior citizens looking after aged parents.

-Caregiver to a parent with a heart/kidney/lung condition, cancer, and vision deficits in a rural setting.

Caregivers call for holistic support for themselves within respite periods, through methods such as yoga classes, massage therapy, and psychotherapeutic counselling. These ideas were brought about by participants; however, other participants felt as though it was hard to step away from their caregiving role when there were not individuals they could fully rely on and trust, to which cost was often a barrier. “Being able to step away when needing a break and have someone responsible to care for your loved one. Home supports that are cost effective.” (Caregiver to a parent with a heart/kidney/lung condition in a large urban setting).

An Ear to Listen and a Shoulder to Lean On

Someone to Turn To. Feeling heard and understood is critical to caregivers feeling supported, which includes feeling supported by family, friends, social groups, healthcare providers, and their communities. “Having someone you can approach, if there is a problem, and you will not feel judged. There may not be an answer to your problem but often all you need is a listening ear.” (Caregiver to a relative with dementia, a heart/kidney/lung condition, and cancer in a large urban setting). Participants reported valuing when they receive flexibility from those around them and when other individuals take the time to listen to their story. In fact, many participants noted that they often just need someone to listen to their story to feel supported. “A doctor who understands. In [our] case the doctor did not understand. Respite care for the caregiver, and or someone to talk to about the situation.” (Caregiver to a spouse with dementia in a small/medium urban setting).
**Supportive Social Networks.** Another caregiver to a parent with dementia in a rural setting described the idea of being grounded by their social network when they said that they appreciate when “family and friends … pull you back into the ‘real world.’” Social networks and having individuals to connect with are so important to caregivers, and participants reported that receiving mental health support and having access to support groups is foundational to facilitating their wellbeing while acting as a caregiver. Unfortunately, not all participants had the opportunity to form these connections. “Most important for me was realizing that I could not continue doing it every day - it was affecting my mental health. I wish there would have been support for me.” (Caregiver to a parent with a neurological disorder in a small/medium urban setting).

The times that have been most difficult over the years have been made manageable by having a social worker/therapist to talk to. I’ve also been in support groups – knowing other people are facing similar challenges is validating. And they often have excellent advice to share which has been very helpful.

-Caregiver to a parent with a neurological disorder in a large urban setting.

I don’t have enough support. I often feel alone and isolated. Siblings stay away as they want to remember mom as she was. My husband and children allow me to vent my feelings and frustrations to a point. My online dementia group helps me to know I am not alone.

-Caregiver to a parent with dementia in a small/medium urban setting.

I would love to be part of an informal support group in my community, that would be my top choice. Individual counseling support from someone who was knowledgeable about aging and caregiving would be great too.

-Caregiver to a spouse with diabetes and arthritis in a small/medium urban setting.

Regarding support groups and networking, participants also reported that they appreciate having access to online support and support via phone. As well, these methods of interaction allowed participants to be more flexible in receiving support.
An easy way to find support. For me it’s not about being able to jump on the phone or go to meetings. Sometimes I’m trapped at home with my loved one who refuses at times to acknowledge their condition and I need help. Online communication or support would be great as I could reach out when I need it without announcing the issues out with her present and allows me to communicate when I can’t leave her alone.

-Caregiver to a parent with dementia in a large urban setting.

Participants truly felt as though a shoulder to lean on would support their mental health, and as mentioned previously, many participants reported not having access to this support in Saskatchewan. Bereaved caregivers are sometimes left to battle with guilt and feelings of inadequacy after their caregiving role comes to an end due to feeling unsupported by the people around them.

Taking care of terminal parents causes several mental health care issues where there was no support for the caregiver, regaining life after loss is extremely difficult as no matter what you did, they die anyhow, but you still feel you failed even though you didn't the disease took them.

-Caregiver to parents with dementia, cancer, and frailty in a rural setting.

**Someone for Backup.** Participants who are facing their caregiving duties alone wish they had someone to share the responsibility of their caregiving role with. Some referred to this as “having backup.” Others noted that care recipients sometimes just need to see a different face other than the primary caregiver, so they called for more companionship from others when the caregiver is away. One caregiver stated they need “someone to take over when needed.”

I want others to share the load of responsibility and assist my mother to have good mental health and not be so alone. She needs more visitors and outings. Mom with some vision loss is insecure about walking. She would benefit from someone taking her out for short walks.

-Caregiver to a parent with dementia in a large urban setting.
Moreover, sharing the responsibility with someone else would allow for extended periods of respite, which participants could sometimes only dream about. “Periodic respite so I could have got away for a few days every few months or even every few years. It would have helped a lot if my sister would have stepped up in that regard.” (Caregiver to a parent with dementia and a heart/kidney/lung condition in a small/medium urban setting). One caregiver in a large urban setting stated they wished for a “24-hour break. Haven’t had one in two years.” Another caregiver in a small/medium urban setting stated “I need someone to give me a break – a few days off for a holiday would be lovely. I no longer have a social life.”

**Optimizing the Care Recipient’s Health**

Participants prioritized receiving support in optimizing their care recipients’ health, which involved ensuring the care recipient has their physical and emotional needs met, has their necessities, is mentally stimulated, is physically active, safe, and receiving the best care possible. The participants shared that if the care recipient’s health is optimized, it facilitates them in allowing the care recipient to age in place.

**Facilitating Easier Access to Care.** To ensure the care recipient is receiving the best care possible, participants said that appointments in Saskatchewan need to be easier to make and happen sooner. They also prioritized themselves having compassion and patience towards the care recipient. Examples of these sentiments in the responses include “Being patient when she asks for help,” “Being emotionally supportive, caring, and compassion[ate]” and “Patience, being strong mentally and not letting him give in.” Lastly, optimizing medication regimes was something participants felt was important to their care recipient receiving the best care.

**Meeting Emotional Needs.** Ensuring emotional needs are met includes assisting the care recipient in coping with their condition, enhancing connection and preventing isolation for the care recipient, ensuring that the care recipient has a sense of belonging and does not feel burdensome, helping the care recipient maintain independence and dignity, and facilitating the care recipient receiving mental health supports, just as the caregiver needs as well. “I never ever want Mum to think that she is a burden to the family.” (Caregiver to a parent with frailty and arthritis in a rural setting). Ensuring the care recipient is mentally stimulated included responses that highlighted the needs of healthcare staff to help prevent loneliness in long-term care. As
well, participants reported needing support in strategizing how to prevent loneliness and isolation in the community.

Ensuring their health needs, physical & emotional needs are met & they are safe. Keeping them up to date on what is current keeps them involved with community as well & connected to the world prevents them from suffering isolation.

- Caregiver to a parent with a heart/kidney/lung condition and cancer in a rural setting.

Encourage involvement with other seniors. Eating healthy and get out and move. Not constantly sitting. Change of environment. Taking her out to see life outside the walls of her independent living suite. Interacts with pets.

- Caregiver to a sibling with dementia in a small/medium urban setting.

**Meeting Physical Needs.** Ensuring the care recipient has their physical needs met encompasses ensuring the care recipient is hygienic and receiving proper nutrition. Many caregivers noted that it is difficult to get the care recipient to maintain proper nutrition, as they report the care recipients having poor appetite and sometimes lack of access to good quality healthy food. Participants made note of how important it is that the caregiver receive information related to the topic of nutrition. Lastly, it was important to participants that the care recipient remains physically active. They need support in keeping the care recipient active through regular outings, walks, and other exercise. Some participants reported the lack of activities for older adults to keep them active. Other caregivers reported the inability to keep themselves active. Throughout many of the responses, it was clear that physical activity also contributes to a healthy consistent routine for both the caregiver and care recipient.

**Healthcare Professionals That Care**

When participants reported interacting with healthcare professionals that were caring and compassionate, they felt more relieved, relaxed, and less burdened. However, those who had negative experiences with healthcare professionals experienced more subjective strain and hardship. Negative interactions also made it more difficult for participants to act as advocates for the care recipients in their caregiving role.
**Trust and Compassion.** Some participants reported that healthcare professionals in some settings did not seem concerned about what they did or how they provided care, which in turn, led to issues with trust and heightened caregiver anxiety regarding the safety of the care recipient. Importantly, participants want their care recipients to receive more personal and individualized care with compassion, rather than to just receive pills once or twice a day.

Staff were at times observed to be rough and insensitive to a resident and then the resident was accused of being aggressive and placed in [sic] antipsychotics, rather than taking an approach to lessen the chance of a reaction from the resident. Some staff were excellent, and others clearly didn’t care…and shouldn’t have been working in that role. Too little supervision and staff were too free to do whatever they wanted and however they wanted to do it. Some care homes have much better reputations than others… but there does not seem to be the desire to determine why? Is it better staff? Better management? More supervision? Better training? There must me some common denominator.

- Caregiver to a parent with dementia in a small/medium urban setting.

We need to be able to trust those assisting our relatives. The elderly need more social supports. Even in level 3/4 facilities, activities that are appropriate should be offered. One activity offered to my mother was making a necklace out of licorice and fruit loops. The staff would put her tv on a cartoon channel and crank up the volume! She was neither demented or hard of hearing. People need to feel as though they are living, not just waiting to die!

- Caregiver to a parent with a heart/kidney/lung condition in a small/medium urban setting.

Having medical staff in both long-term care and hospitals that have the training, time, patience, and stamina to truly provide gentle and effective care - not just hand out pills and stick to their schedules. I know there are many who truly love their patients, but they have no time to let them know it in tangible caring ways.

- Caregiver to a parent with dementia in a small/medium urban setting.
**Allied Healthcare Professionals.** Participants recognized the value of allied healthcare professionals, such as physical therapists, occupational therapists, social workers, and dietitians; however, they express dismay at how hard it is to access help from these allied health professionals, especially when situated in the community.

Sometimes you need a break. I found CPAS [Client Patient Access Services] very supportive in terms of proving routine nursing support and care assistants for specific tasks such as lunch preparation. It was also possible to access nutrition and occupational therapy advice, which was very helpful. The challenge is staff shortages and limited hours of operation. Routine is very important for care recipients but that is difficult to establish with care services.

- Caregiver to a parent with dementia and a heart/kidney/lung condition in a large urban setting.

Adequate physiotherapy, occupational therapy, and home care for senior citizens, so they could have the best possible quality of life and families would not have to provide these services out of pocket. For example, my father is in a public care home where he is only eligible for one physio appointment a month.

- Caregiver to a parent with dementia, frailty, and mental illness in a large urban setting.

**Bedside Manner and Including the Caregiver.** Participants reported that poor bedside manner received from healthcare professionals was discouraging. Participants shared that they want to receive appropriate care, free of judgment. They want to be recognized with the care recipient as a caring dyad and treated as an equal member of the healthcare team.

They need to be respected in spite of age. For example, taking my mom to a skin specialist due to a rash, the specialist suggested her rash came out of the sky and when giving her a prescription for ointment, handed it to me rather than her! Very disrespectful.

- Caregiver to a parent with a heart/kidney/lung condition in a rural setting.
My biggest concern is that medical professionals say, "They're old. Problems are expected at this age." Or "They're mentally [challenged]. What do you want me to do?" This has happened. Caregivers want to be heard and respected. When talking to caregivers and senior or mentally compromised patients, use simple language, not medical verbiage, speak to them in a slow clear voice and approach giving them time to answer. Asking how the caregiver is doing. Providing all the options for care like Homecare, Seniors Support Services, drug assistance plans, income subsidiary information, Senior's drug plan, exceptional drug status, just to name a few. And then helping those who have no caregivers gain access to these services or show caregivers pathways, give phone numbers to services.

- Caregiver to a parent and sibling with a neurological disorder, heart/kidney/lung condition, cancer, and arthritis in a small/medium urban setting (unable to discern the specific conditions of each care recipient).

When my mother was dying in a long-term care facility, I had to go to nursing management to have her care plan include proper positioning, care of bed sores & pain management. My mother was unable to speak & express her needs. Pain meds were often 2-3 hrs late and I had to find staff to remind them. This was not always met with pleasantness from staff.

- Caregiver to a parent with dementia and a heart/kidney/lung condition in a large urban setting.

Since the caregiver is often the person who spends the most time with the care recipient, they feel as though they know the care recipient’s situation well. However, some participants reported not having their insights valued when the care recipient was receiving assessment by healthcare professionals. As such, participants call for enhanced communication between healthcare professionals and themselves and want to be included in the healthcare professional’s assessment of the care recipient.
I also wish there were more structure or similar rules doctors followed to allow families to seek help for their loved ones. In the beginning, we tried to tell my aunt’s doctor that there was something wrong. He would talk to my aunt, who is quite convincing, and she would say there was nothing wrong with her and we were just trying to put her in a home.

-Caregiver to a relative with dementia in a large urban setting.

**Specialized Dementia Training.** Receiving a diagnosis of dementia is devastating to many, and responsive behaviours in dementia were reported to complicate receiving care. Participants called for healthcare professionals to receive specialized training in dementia friendly care.

Dementia diagnosis, after care, an actual doctor that has some experience and provides care instead of sending the person home to struggle alone and scared!! When the time comes a care home that actually has experience with dementia and proper treatment and care for the [person living with] dementia and family!!

-Caregiver to a parent with dementia and a heart/kidney/lung condition in a small/medium urban setting.

**Improved Policies, Legislations, and Regulations**

Finally, the participants called for improved policies, legislations, and regulations to better assist them in their role, which included financial support and support in the workplace for those juggling caregiving and working.

There’s not enough legislation that allows for long term caregivers [to receive] the understanding and acceptance they need. Familial accommodations in the workplace can be done when young families are having difficulties accessing day cares, etc. When you’re caring for an older adult, the patience or tolerance isn’t the same. There is an unwritten expectation that your parent can be ‘placed in respite’ or ‘admitted to LTC’ when there is conflict between caregiving and working.

-Caregiver to a parent with frailty in a large urban setting.
I would like to have tax credits or some other sort of compensation for those of us who dedicate unpaid time to caring for aging relatives. I also would like to see some sort of legislation protecting the jobs of people who need to take time away from work to care for an aging relative, and ensure we are entitled to receive EI if we need to stop working to provide full time care for a certain period of time. Similar to parental leave.

-Caregiver to a parent with a heart/kidney/lung condition and cancer in a large urban setting.

**Not Qualifying for Services and Support.** Staffing issues in healthcare and long-term care were recognized to be a barrier to care recipients receiving adequate care, which in turn placed more strain on the caregivers. As well, there were often small and seemingly insignificant factors that led to care recipients not qualifying for services, such as Meals on Wheels or even long-term care altogether. One caregiver to a parent with dementia, a heart/kidney/lung condition, and cancer in a rural setting stated “Very difficult to get support when needed. So many hoops to jump through, only to be told we don't qualify.” This barrier is frustrating for the participants, and once again, more strain is placed on the caregivers.

LTC is not adequate in our province. Mom’s quality of life would have been so much better, had she been able to be around other seniors and not alone once mobility became an issue. Was told the only way she qualified for Meals was if she couldn’t get out even for a doctor’s appointment, how unrealistic is that excuse. When her final fall resulted with her being hospitalized and waiting LTC, she wasn’t properly cared for and ended up with pressure sores. Again, not enough staff and hospital staff are not trained in that area, they only look after the sick.

-Caregiver to a parent with dementia, a heart/kidney/lung condition, cancer, and post-stroke in a rural setting.

**Affordable Assistance and Care.** Participants noted Saskatchewan’s lack of intermediate care facilities but also the lack of affordable assistance and care. It was echoed by participants in all geographic settings throughout responses that “caregiving is a full-time job
with no pay.” Therefore, it makes it incredibly difficult to afford supportive care when there is limited income received due to the time being a caregiver takes.

It would be nice to have access to a care home that isn’t at the level of long-term care but where there is meal prep and supervision, delivery of meds. Basically, a private care home that isn’t $3000 + a month. The government top up isn’t nearly enough for low-income seniors.

-Caregiver to a parent with dementia in a small/medium urban setting.

**Lack of Government Funding and Support.** Participants called out the lack of government funding to facilitate caregivers keeping the care recipients in the community to age in place. They also expressed their dismay at the lack of tax breaks and subsidies for caregivers. “SK Government tax breaks for full time caregivers. What is offered now does not even cover one month’s expenses - i.e., time off from work and travel to city as rural has no support” (Caregiver to a parent with dementia in a rural setting). They reported needing more financial assistance to hire relief and also mental health supports for themselves, as many could only access services such as counselling if they had private benefits.

The health care system is too medically, and facility driven and is almost impossible to access unless the patient goes through emergency services. There are not enough financial resources for staff to be trained and available for care for clients and to relieve the burden from family members. Trained caregivers should be provided, trained, and qualified, and accessible for at minimum 12 hours per day. Caregiving in a client’s own home places less burden on the healthcare system financially, bed availability and staff burden. How we treat our elderly and infirm is a reflection on our society. Having recently gone through the role of caregiver, I can say that our system does not look after these people well! There are many kind individuals along the road, but the system causes more stress and burden for the caregiver who also need to be supported.

-Caregiver to a parent with cancer in a rural setting.
Support in the Workplace. When participants had supportive workplaces, their worlds were made easier to cope with. On the other hand, when participants did not have supportive employers, their role was made much more difficult. Participants stated that it is often difficult to take any time off work and those without family supports are the ones who struggle the most with this. Some participants mentioned needing to use up their vacation time to fulfill their role as a caregiver. Many compared caregiving for older adults to parenting children, since parents are more easily afforded time off to provide care to their children, but the standard is not set to be the same with caregivers to older adults.

Resources such as others you can rely on to pick up some of the care provider roles when I am unable. Having a supportive workplace has been helpful- understanding when I need to be flexible with my work time so I can get my parent to appointments and check in in them

-Caregiver to a parent with frailty in a large urban setting.

It is important that employers allow special days for times she needed me as I was the only family member nearby to help her. This is a societal issue and therefore health care providers can’t help in this department.

-Caregiver to a parent with dementia and post-stroke in a rural setting.

Question 4: Additional Open-Ended Comments from Caregivers

The final open-ended survey question was: “Is there anything else you would like to add about the experiences, perspectives, and priority support needs of caregivers in Saskatchewan?” Most of the responses to this question were either elaborations or summaries of what the participants had already reported in questions 1, 2, and 3. Many caregivers also took this question as an opportunity to thank the student researcher for providing them with “a place to vent” or opportunity to share their story, with others indicating that completing the survey was therapeutic. Although the rest of the responses to this question include relevant and useful data, they unfortunately did not contribute to answering the research questions of this study. Therefore, the data from this question is saved for later analysis using an alternate research question.
Chapter Summary

When approaching synthesis of the findings presented within this chapter, it is important to reflect on the initial research questions and study objectives that were put forth in Chapter 1. The research questions for the study were: (1) What are the challenges and positive aspects of the caregiver experience in Saskatchewan? (2) What do caregivers to older adults in Saskatchewan identify as priorities for support? The objectives were to: (1) Explore informal caregiver experiences in both large urban and small centre or rural areas of Saskatchewan; and (2) Identify caregivers’ priority support needs to facilitate their caregiving role.

The presentation of findings was structured by sharing the main findings from each individual survey question. For the first research question, the challenges that Saskatchewan caregivers face were found to be related to internal and external climates. Regarding the internal climate, caregivers were challenged with their emotions, such as fear, guilt, loneliness, hopelessness, and inadequacy. The external climate involved challenges that were systems-based, which included barriers within the healthcare system and financial stress related to caregiving activities. Positive aspects of the Saskatchewan caregiver experience were almost entirely based on emotional involvement with the care recipient. Having the ability and opportunity to care gave caregivers the opportunity to give back to the care recipient. Caregivers experience personal growth through acting in their role and can even develop a sense of pride in what they are doing to help the care recipient. The breadth, detail, and sheer number of responses to the first two survey questions truly captured what caregivers in Saskatchewan experience in their role.

The first study objective involved exploring the experiences of urban and rural caregivers in Saskatchewan. It was determined through several reviews of the written responses that the experiences of urban versus rural caregivers were not actually that different. Both urban and rural caregivers reported similar positive aspects to the caregiving role and challenges within the internal climate. Where differences lay are in the challenges, due to the increased barriers to care that exist in rural Saskatchewan. However, caregivers in both large urban and small/medium urban settings reported barriers as well. The remoteness of rurality accompanied unique challenges such as access to adequate transportation and the absence of telehealth or mobile health interventions. The second research question and study objective align, as they revolved around developing support priorities for caregivers in Saskatchewan. Many support priorities
echoed the challenges that caregivers identified in question one, such as receiving validating care from healthcare professionals and feeling supported by individuals in their lives. Other support priorities were stated more directly, such as caregivers wanting respite, and access to online and in-person support groups. These priorities will be further discussed and situated within the wider body of literature in Chapter 5.
CHAPTER 5: DISCUSSION

This chapter is structured to discuss the findings from the three main survey questions in the study individually. Under each heading, the overarching categories are situated within the wider body of caregiving literature. Highlights from the study will be explored and what the study adds to the literature will be described. The strengths and limitations of the Saskatchewan Caregiver Experience Study will be presented. Lastly, implications for research, practice, education, and policy are provided.

Challenges Experienced by Caregivers

In Chapter 1, the conceptual definition of caregiving for this thesis study was provided from the concept analysis by Hermanns and Mastel-Smith (2012). They defined caregiving as a process of helping another person in physical, mental, emotional, and social domains when that person is unable to do so for themselves (Hermanns & Mastel-Smith, 2012). This definition highlights the complexities of the caregiving role, which are undoubtedly associated with challenges. Caregivers are burdened significantly by the necessity to adjust to new roles while dealing with unclear responsibilities (Olesen et al., 2022). As such, it comes as no surprise that participants reported a breadth of challenges exist in their caregiver experience in Saskatchewan.

Caregiving is Exhausting

It was clear from participant responses that caregiving can be exhausting and emotionally taxing, which has been iterated significantly in previous literature. Emotional exhaustion is defined as feeling overloaded, unable to continue, and drained when facing the caregiver experience (Gérain & Zech, 2019). A qualitative study of caregivers to persons living with dementia by Ploeg et al. (2020) saw participants describe their gamut of feelings using the terms “emotional, exhausted, and on edge,” with one participant stating “It’s a very debilitating disease not only for the [person] but for the family. It almost makes you numb.” (p. 2609). Participants also reported feelings of guilt in this thesis study, which highlights the tension that is associated with feelings of moral obligation to their families. Feelings of resentment towards care recipients and other family members was also noted by participants. Caregivers have previously reported resentment and depression as two responses to providing care to a care recipient who exhibits controlling and manipulative behaviour (Johnson et al., 2022; Martin-Cook et al., 2003). It has also been found that the pre-caregiving bond between the caregiver and care recipient is not entirely protective of the caregiving bond between the caregiver from depressive symptoms and feelings of resentment.
Lastly, participants in this thesis study reported an exhausting challenge was the stubbornness and state of denial some of their care recipients were living in. Caregivers in other studies have reported similar behaviours, especially at the onset of illness. For example, Hejazi et al. (2021) undertook a qualitative study of caregivers to patients on hemodialysis. The caregiver participants in their study reported that the care recipients began to exhibit abnormal and inappropriate behaviours shortly after initiating hemodialysis, citing stubbornness and resistance to receiving any advice that was undesirable to them (Hejazi et al., 2021).

“Living My Own Life”

Juggling additional responsibilities such as parenting children and maintaining employment was reported by participants. As the population ages, there is a growing number of individuals who find themselves providing care to older adults while satisfying their other commitments such as employment and childcare (Clancy et al., 2020). Caregivers who hold the responsibility of childcare and caregiving to older adults have been referred to as being ‘sandwiched’ (Duxbury et al., 2022) or part of the ‘sandwich generation’ (Fast, Dosman, et al., 2013). Jewell et al. (2022) conducted a study of Indigenous caregivers in Ontario and found that caregivers are overwhelmed when attempting to meet the demands of their families and communities. In their study, one caregiver to aging parents cited the guilt she felt when acting in her caregiving role because she was not able to be with her children and her partner, stating: “I couldn’t spread myself thin enough” (Jewell et al., 2022, p. 6). Providing both childcare and caregiving may lead to psychological strain and time conflicts; however, the consequences of caregiving differ from those of providing childcare, as the greatest challenge reported by individuals in this complex situation is the unpredictability of when and how long they will need to be in their caregiving role (Clancy et al., 2020).

In 2017, 28% of Canadians (8.1M) reported acting as informal caregivers and approximately three quarters of this group (6.1M) were employed during their caregiver experience (Vanier Institute of the Family, 2020). Caregivers who are employed spend significantly more hours per week providing care, and report conflicts with their employers, mental and physical health problems, less time for leisure and other family members, and family conflict (Sadavoy et al., 2022). Specific to gender, women who are part of the sandwich generation are 1.6 times more likely than men to have to reduce their hours of work to accommodate their caregiving responsibilities (Fast, Dosman, et al., 2013). Sadavoy et al. (2022)
quantitatively studied the impact on employees providing informal caregiving to persons living with dementia. They found that there were high levels of caregiver role strain, work interference, and absenteeism from work in their sample of Canadian caregivers (Sadavoy et al., 2022), which similar findings were faced by caregivers in this Saskatchewan thesis study as well. In a study of Albertan caregivers, men and women who spent more than 20 hours per week providing care were respectively 3.4 times and 2.4 times more likely to be absent from work (Fast, Dosman, et al., 2013). Working to connect employed caregivers to resources such as social or financial support has the ability to empower them as they strive to balance between working and caregiving responsibilities (Xiang et al., 2022). However, in Saskatchewan, these resources need to be more clearly defined and accessible.

Navigating Complex Systems

Saskatchewan’s healthcare system was regarded as fragmented by participants in this thesis study, as they lamented at the lack of consistency in accessing and receiving healthcare services in the province. Caregivers frequently function as care coordinators to advocate for their care recipients, as they attempt to navigate the complexities of the healthcare system without assistance from professionals (Findlay et al., 2020). Furthermore, rural Saskatchewan residents face challenges with accessing the healthcare system from a distance. Rural participants reported the lack of allied health professionals in their areas as a challenge to receiving coordinated care. The involvement of allied health professionals in care teams, such as dietitians, occupational therapists, and physical therapists, has been found to reduce appointment burden for both patients and caregivers and provide a more seamless care experience (Findlay et al., 2020; Luckett et al., 2017; Sheehan et al., 2021; Smith et al., 2021) but these professionals can often only be accessed during a hospital admission. For care recipients being discharged from the hospital setting, better communication between hospital providers, homecare providers, and caregivers is needed to improve care coordination and facilitate healthy recovery at home (Dossa et al., 2012). Navigating the complexities of the healthcare system is complicated further when both the caregiver and care recipient are living with chronic conditions. Many older Canadians are increasingly relied upon to take on caregiving, even though they may experience health issues of their own (Arriagada, 2020).

The complexities of governmental systems also create challenges for caregivers. Participants in this thesis study noted that Saskatchewan’s current systems are not oriented to
older adults aging in place. Limited and lack of funding and resources leads to uncertainty in the accessibility of care, when government cuts cause major scaling in program availability (Smith et al., 2021). Overly restrictive eligibility criteria, convoluted and repetitive application processes, and other gatekeeping mechanisms are a few layers of red tape caregivers must cut through to access government support (Magnaye et al., 2020). While there is increasing recognition within government policies of the contribution of caregivers, financial support often comes with a trade-off such as restrictions on employment, which limits opportunities for managing financial burden (Gardiner et al., 2019). For support in providing care at home, the most basic form of financial support Canadian caregivers can receive is a federal tax credit, yet only a small minority qualify (Sinha, 2013) and government portals for tax information are also difficult to navigate (Stall, 2019). Moreover, caregivers have reported difficulties in making sense of eligibility requirements and maneuvering application systems while juggling the demands of their role (Gardiner et al., 2019).

“Am I Doing it Right?”

Caregivers need to feel as though they are doing the right thing with their care labour to achieve well-being and satisfaction in their role (Moreno-Cámara et al., 2019). In many cases, caregivers express being unprepared for the impact of their caregiving role (Durante et al., 2019; Findlay et al., 2020). To mitigate this unpreparedness along the trajectory of an illness such as dementia, caregivers have reported that they must be psychologically primed for what is to come to be able to effectively cope (Moreno-Cámara et al., 2019). The accruement of knowledge helps caregivers advance in their role and allows them to both prevent and cope with difficult situations (Lindeza et al., 2020). In a study of caregivers to older adults with heart failure, many caregivers described a lack of confidence in monitoring signs and symptoms, since healthcare professionals did not provide them with this critical knowledge (Durante et al., 2019). The participants in this thesis study described similar experiences, which was referred to as “going it alone.” A participant in the study by Durante et al. (2019) stated: “Nobody gave suggestions to us, so I had to develop strategies that helped me to keep my husband’s situation under control, but I don’t know if what I do is correct” (p. E31). Taking into consideration the weight that rests on the shoulders of caregivers in terms of responsibilities, receiving reassurance and validation in their caregiving abilities from social networks and healthcare professionals directly relates to enhanced confidence, competence, and strength in the caregiving role (Mueller et al., 2022).
Caregiving at a Distance

Caregiving at a distance was narratively found to be a component of many of the participants’ caregiver experience in this study. Geographical proximity is an important structural factor that determines the extent of a caregiving exchange (Li et al., 2019) and also causes transportation to become a barrier (Ratnapradipa et al., 2022). It is common for adult children to move away, leaving parents with an ‘empty nest,’ which is especially true for those living in rural areas (Chang et al., 2022). With younger generations leaving rural areas, usually in search of work, the older generations who are often of lower income are left behind (Mihailescu, 2021). It has previously been reported that providing transportation is the most common task for Canadian caregivers (Sinha, 2013) which is complicated by greater physical distances between caregivers and their care recipients. Moreover, adult children who live more than 30 minutes away from their aging parent care recipients have been found to experience higher levels of depressive symptoms compared to adult children living within a closer proximity (Li et al., 2019). With depression and anxiety being noted throughout the responses to this thesis study’s survey, Saskatchewan caregivers who are distanced from their care recipients could be experiencing similar effects. Consequently, monitoring for depressive symptoms in caregivers who are caregiving at a distance should be taken into consideration by Saskatchewan healthcare professionals.

Positive Aspects of Caregiving

It has been well-iterated in literature for many years that positive aspects of caregiving should be considered when supporting caregivers, as the focus should not only reduce the difficulties they face, but also enhance the positive aspects of their role (Grant & Nolan, 1993; Kramer, 1997a, 1997b; Lévesque et al., 2002; Louderback, 2000). Through this approach, caregivers’ well-being can be reinforced and the impact of stress and burden in caregiving can be reduced (Carbonneau et al., 2010). As such, it was imperative to explore the positive aspects of the caregiver experience in Saskatchewan.

Caregiving is Rewarding

Participants in this study largely discussed the rewards of caregiving as a positive aspect. They mentioned rewards such as getting to treasure time with the care recipient, learning the care recipient’s life story, and sentiments such as love, appreciation, and dedication. The rewards of caregiving are an important construct that is less-explored in research but often experienced by
caregivers (Pendergrass et al., 2019). From a caregiver stress perspective, caregiving harms psychological well-being, whereas a caregiver reward perspective suggests that the provision of care benefits psychological well-being (Lee et al., 2020). In a study of experiences of family caregivers to persons living with dementia, participants made note of the caregiver stress perspective, citing their feelings of loneliness, frustration, stress, and fatigue (Harris & Titler, 2022). Despite this, all participants were able to identify rewarding aspects of caregiving, which included increased togetherness, new opportunities, and a greater appreciation for the little things in life (Harris & Titler, 2022), which align with the findings from this thesis study. Caregiver participants in the study by Hebdon et al. (2022) identified that most caregiving rewards are intrinsic, focusing on relationships with greater closeness and understanding, personal growth, and the ability to be there for the care recipient. These intrinsic rewards also overlap with the other categories which were crafted from content analysis of this thesis study’s data. Overall, it is recognized that providing adequate support and enhancing coping can help to maximize caregiving rewards while minimizing adverse health outcomes (Hebdon et al., 2022).

**Having the Ability and Opportunity to Care**

This category involved caregivers appreciating the ability and having the opportunity to engage in their caregiving role. Participants reported feeling fortunate to be caregivers and foster independence and quality of life in their care recipients. Ensuring the care recipient feels safe and “giving back” to the care recipient were facets under this category. In the study by Harris and Titler (2022), the opportunity to be a caregiver was one of the most prevalently mentioned positive aspects of the caregiver experience. The act of caregiving has been found to provide caregivers with a sense of giving back to their care recipients and an increased sense of meaning and purpose in life (Anderson et al., 2019; Haan et al., 2021; Hango, 2020). For example, bereaved caregivers acknowledge the exhaustion they felt in their role but many still feel grateful for being able to have enjoyed moments with their care recipients, and honoured to have been able to provide family care (Haan et al., 2021).

Feelings of altruism and activism help caregivers cope with and reframe stressful caregiving experiences, which supports a sense of meaning in caregiving (Anderson et al., 2019). Feelings of reciprocity also exist, especially in the case of adult children as caregivers who want to support their parental care recipients by “giving back” the care they received when they were young (Herbst et al., 2022; Rodrigues et al., 2022). Perhaps most importantly, the facilitated
ability to be a caregiver is critical to satisfaction. Participants in this thesis study cited that having adequate access to respite facilitated their caregiving role. Accessible respite has been quantitatively explored in the study by Hogan et al. (2022), in which findings showed that caregivers who had access to respite self-reported lower perceived stress and depressive symptoms, only mild-to-moderate burden, and as such, a higher overall satisfaction in caregiving.

**Ensuring Quality Care for the Care Recipient**

Ensuring quality care for the care recipient involved knowing everything about the care recipient’s situation, ensuring safety, providing comfort, and advocacy. Notably, providing comfort through symptom management was an important positive aspect of the caregiver experience by participants in this thesis study. Higher levels of preparedness to manage symptoms helped individuals feel more prepared to transition into their caregiving role (Prater et al., 2022), which aligned with the findings from this thesis study, as participants who had healthcare backgrounds and transitioned to the role of family caregiver reported that their experience facilitated their feelings of accomplishment in caregiving. As well, knowing the care recipient’s whole situation allows for the ability to be an advocate to ensure quality care. In the literature, the role of advocacy has been shown to help caregivers achieve self-actualization and effective self-care practices (Sabo & Chin, 2021). Therefore, being ‘in the know’ and advocacy allow caregivers to confirm their care recipient is receiving quality care (Hvalič-Touzery et al., 2022).

**Personal Growth Through Being a Caregiver**

Caregiver burnout has been referred to as tridimensional (Gérain & Zech, 2019). The first two dimensions are emotional exhaustion and depersonalization, depicting the negative effects of caregiver burnout (Gérain & Zech, 2019). However, the positive dimension of caregiver burnout is a sense of personal accomplishment where, despite burnout, the caregiver may gain a sense of fulfillment through their caregiving role and find meaning in it (Cross et al., 2018). Participants in this thesis study cited self-validation through knowing that they were making a difference and learning more about themselves. In a study by Peacock et al. (2010), participants acknowledged their personal growth that occurred as a result of caregiving to a person living with dementia. “Isn’t that just the way this journey is, is constantly adapting, moving on, and adapting again and moving on” (p. 648) was stated by a participant when recognizing the transition and growth that
occurs over a period of time spent caregiving (Peacock et al., 2010). Caregiving gives individuals the opportunity to discover more about themselves and skills that are attained through caregiving can foster confidence in handling challenging situations that arise other aspects of life (Peacock et al., 2010). Moreover, identification of meaning in the caregiver experience can be considered a protective factor for reducing emotional distress (Palacio & Limonero, 2020) and a mediator for resilience (Opsomer et al., 2022). The resilience process in caregiving is influenced by contextual elements such as individual history, sociocultural background, caregiver characteristics, and the behaviour of the caregiver’s supportive network (Opsomer et al., 2022). Promoting a resilient coping style in caregivers can diminish the risk of stress and burden, and facilitate abilities for adaptation to new challenges (Palacio et al., 2020).

**Caregiving is Not a Positive Experience**

Caregivers in the thesis study who responded that caregiving was not a positive experience did not go into detailed explanation as to why they had this perspective. However, there are interesting features within the wider body of literature that could provide insight into why some caregivers are unable to identify positive aspects in their role. Studies that explore the associations of positive and negative dimensions of caregiving with caregiver well-being are scarce (Quinn et al., 2019). The idea of role captivity was proposed by Pearlin et al. (1990) and was described as caregivers feeling trapped in the caregiving role. In a longitudinal cohort study, Quinn et al. (2019) found that higher scores on the 3-item Role Captivity scale (Pearlin et al., 1990) correlated with lower scores on the Positive Aspects of Caregiving scale (Tarlow et al., 2004), resulting in lower overall caregiver well-being. As such, it is possible that due to the paucity of resources available to caregivers in Saskatchewan that were identified within this study, some participants may feel trapped in their caregiving role with inadequate support. Lindeza et al. (2020) conducted a systematic review of qualitative studies that explore the positive and negative aspects of caregiving through caregivers’ perspectives. It was found in their review that emotional and social aspects experienced by caregivers, such as feelings of loneliness, guilt, grief, and uncertainty contribute to their negative appraisal about caregiving (Lindeza et al., 2020). These sentiments were highlighted in this study’s responses to the first question regarding the challenges of being a caregiver, which could explain why a number of participants within this study responded that there were no positive aspects to the caregiving role. On the contrary, the same systematic review found that medical counselling and formal care
support contribute to positive appraisal of the caregiving role (Lindeza et al., 2020). These findings, in turn, shine light upon the need to intervene and support Saskatchewan caregivers psychologically through the difficult emotions experienced while caregiving.

**Support Priorities of Caregivers**

The scoping review in Chapter 2 compiled the support priorities of caregivers that have been identified in previous literature. Although there are facets of similarity, the support priorities identified by the participants within this thesis study were different. This difference in support priorities indicates that Saskatchewan has a unique landscape of caregiver needs.

**“Help When We Need It!”**

Information needs, the need for respite, and assistance with transportation fell under this category. It is an increasingly regular expectation that caregivers acquire sophisticated understanding of their care recipient’s condition, as well as new skills to execute complex medical or nursing tasks (Bell et al., 2019). Despite these tall and pressing responsibilities, caregivers are also expected to complete these tasks without adequate preparation and support (Bell et al., 2019). Caregivers who report lack of care coordination, respite breaks, continuity of care, and difficulties with prioritizing their own needs have been found to have poorer self-care behaviours (Oliveira, Zarit, et al., 2019). In a community assessment of caregivers in Saskatoon (Hall & Holtslander, 2022), caregivers reported they need better access to respite services, which was echoed by participants across the province in this thesis study. The mental health effects of providing respite to caregivers are numerous, including an improvement in life satisfaction, overall wellbeing, and a decrease in self-reported depressive symptoms (Costa-Font & Vilaplana-Prieto, 2022).

Participants in this thesis study also noted the physical strain of the caregiving role. Caregivers can have their own physical limitations that make providing care difficult (Oliveira, Vass, et al., 2019; Oliveira, Zarit, et al., 2019). Anxiety accompanies this physical strain, as caregivers sometimes worry about the fact that their health issues may eventually prevent them from caring for their care recipient (Oliveira, Vass, et al., 2019). With one in four older Canadians acting as caregivers to their spouses (Arriagada, 2020), it is imperative to ensure sufficient help exists as the physical aspects of caregiving become more demanding, which also holds true for younger caregivers (Koumoutzis et al., 2021).
Transportation is a frequently reported barrier to care, which necessitates the involvement of caregivers in providing this service (Bell et al., 2019). For those in rural settings, participants in this thesis study reported that transportation is even more complicated due to the extended distance needed to travel to appointments. In a study of barriers and facilitators to stroke recovery (Magwood et al., 2019), community ride-sharing programs have been found to be facilitators that mitigate transportation being a barrier.

**An Ear to Listen and a Shoulder to Lean On**

Support from social networks and healthcare professionals is a key facilitator to caregivers’ self-reported life balance (Brooks et al., 2022; Rossau et al., 2022; Tokovska et al., 2022). Caregivers have previously reported how caregiving limits their social lives and brings on psychological strain (Rossau et al., 2022). When psychosocial support is provided to caregivers in a comprehensive and systematic way, caregivers are enabled to handle the emotional, cognitive, and behavioural consequences of their role (Tokovska et al., 2022). Caregivers to persons living with dementia widely endorsed the value of support groups, which offered companionship as well as information, noting the opportunity to meet others who were experiencing similar situations is therapeutic (Toms et al., 2015). There is also stress, depression, loneliness, guilt, and grief when caregivers reach a point where they need to place their care recipient in care (Brooks et al., 2022). Brooks et al. (2022) reported that psychoeducational and psychosocial supports help caregivers to better cope with the stressors and losses experienced during the transition from caregiving at home to caregiving in the periphery while care recipients enter professional care settings. As these findings from previous studies align with that of those in this thesis study, psychoeducational and psychosocial supports should be amplified where existing, and made available where absent within Saskatchewan.

**Optimizing the Care Recipient’s Health**

This category was developed from the participants’ responses related to support in meeting the physical and emotional needs of care recipients. Caregivers often engage in protective behaviours to safeguard their care recipient’s physical and emotional wellbeing, which can result in detrimental effects on the caregiver (Jeyathevan et al., 2019). Caregivers play a crucial role in optimizing their care recipient’s health and well-being. Caregivers act as advocates, share in decision-making, and also provide basic care such as feeding, hygiene, and socialization (Nash et al., 2021). Regarding optimizing the emotional health of care recipients,
caregivers to individuals with spinal cord injuries noted that they hide their distress related to caregiving from care recipients to protect the care recipient from feeling guilty (Jeyathevan et al., 2019). In their study of cancer caregivers, Sun et al. (2019) called for interventions that provide personalized support to caregivers in meeting the physical and emotional demands of the care recipient’s cancer. Most caregivers strive to provide high-quality care (Meyer et al., 2022). It is clear from the findings within this thesis study and in the wider body of literature that caregivers need more support in ensuring the care recipient has optimized health conditions. When this is not the case, caregivers report strain in relationships and higher levels of stress related to their role (Meyer et al., 2022).

**Healthcare Professionals That Care**

Situating this thesis study’s findings within the wider literature can help to assist Saskatchewan healthcare professionals in their provision of effective and inclusive care. Caregivers often feel unprepared for their caregiving role and consequently require additional support from healthcare professionals for the practical aspects of caring and general information regarding the care recipient’s conditions (Becqué et al., 2019; Cochrane et al., 2022). Caregivers often act as primary information seekers and need to be able to act on the information retrieved to be able to better understand and manage the care recipient’s conditions (Cochrane et al., 2022). As well, to reduce feelings of uncertainty, caregivers report wanting information regarding the care recipient’s prognosis and life expectancy when facing life-limiting illnesses (Preisler et al., 2019). Appointments with healthcare professionals are an opportune time to conduct this gathering of information, which highlights the importance of having a caregiver present during appointments (Cochrane et al., 2022). A finding from this thesis study was that participants prioritize respectful and helpful bedside manner from the healthcare professionals they interact with and want to feel included during the care recipient’s appointments. Caregivers in the study by Cochrane et al. (2022) viewed interactions with healthcare professionals as their main opportunity for accessing information, although when they felt uncomfortable with the healthcare professional, they were more reluctant to ask questions.

A systematic review of nursing interventions to support caregivers in home-based end of life care by Becqué et al. (2019) found that the interventions were based on four domains: (1) psychoeducation; (2) needs assessments; (3) practical support with caregiving; and (4) peer support. However, psychoeducation was the most frequently occurring domain within these
nursing interventions (Becqué et al., 2019), which involved the provision of general information regarding the care recipient’s condition (Bužgová et al., 2016; Funk et al., 2010; Harding et al., 2012; Hudson et al., 2004). The impact of psychoeducational interventions on caregivers has been found to support caregivers in self-management, which in turn enhances psychological well-being (Verkaik et al., 2015). Self-management involves helping individuals living with long-term conditions to manage their condition and cope with its physical and emotional symptoms (Lorig & Holman, 2003). However, self-management is not only a task for patients but also for caregivers (Verkaik et al., 2015). While support within the clinical setting is important, it is clear from this study’s findings that healthcare professionals should strive to encourage and enhance self-management within the community. Family caregivers to older adults with cancer have previously reported that it is a “lifeline” (p. 5) when healthcare professionals work to support self-management practices within the caregiving dyad (Pethybridge et al., 2020). In a study by Pethybridge et al. (2020), healthcare professional traits that were especially appreciated by the caregivers to older adults with cancer included supportive, caring, sympathetic, and informative. In fact, being able to contact healthcare professionals to ask questions when uncertain about cancer-related symptoms was found to lessen stress and improve confidence in caring among caregivers (Pethybridge et al., 2020).

**Improved Policies, Legislations, and Regulations**

Within this category’s title are three terms that need to be clearly defined: policies, legislations, and regulations. *Policies* are defined as actions which contain goals and the means to achieve them, and public policy involves a fundamental choice on the part of governments to do something or to do nothing with respect to a problem (Howlett & Cashore, 2014). Policies go on to form *legislations*, which are laws (often referred to as Acts) that are enacted by governments (Health Canada, 2006). An example of legislation in the context of caregiving could be a law that reinforces federal and provincial-level policies to support caregivers (Dawson et al., 2020). Lastly, *regulations* are a form of law, which define the application and enforcement of a legislation (Health Canada, 2006). While policies for caregivers exist at provincial and federal levels, Saskatchewan currently has no legislations related to supporting caregivers. In 2011, the Legislative Assembly of Manitoba (provincial government) passed a legislation entitled the Caregiver Recognition Act. However, this legislation did not provide defined regulations for the provision of caregiver support, and rather served to acknowledge the
existence of caregivers in Manitoba by proclaiming the first Tuesday of April to be “Caregiver Recognition Day” (Legislative Assembly of Manitoba, 2011). While Saskatchewan has legislated a similar recognition entitled “Seniors’ Week in Saskatchewan” (Government of Saskatchewan, 2022), recognition of the role of caregivers is only celebrated unofficially through “Caregivers Week” by non-profit organizations (Saskatchewan Seniors Mechanism, 2022). The lack of official recognition of caregivers to older adults, in addition to the lack of legislation to support them, is problematic for the Province of Saskatchewan. In fact, one of the few supports available for older adults in Saskatchewan is the “Personal Care Home Benefit,” which provides seniors with monthly financial assistance to help with the cost of living in a personal care home or long term care (Government of Saskatchewan, 2020), further emphasizing that Saskatchewan’s current governmental climate does not support aging in place.

Canada’s long term care system has been criticized in policy for needing an ‘overhaul’ (Flood et al., 2021). Challenges that Canadian policy-makers face involve not only adequately meeting the growing needs for long term care services, but also ensuring that those services are delivered where people want to receive them, which is most often at home (Flood et al., 2021). Cash-for-care benefits are direct public transfers paid to caregivers to support care at home, and are widely implemented in countries such as Germany and the Netherlands (Flood et al., 2021). However, as of 2021, Nova Scotia is the only Canadian province to implement a cash-for-care caregiver benefit program, in which caregivers receive a sum of $400 per month (Mihailescu, 2021). Although Nova Scotia’s aging population is parallel to that of Saskatchewan’s, Nova Scotia took the initiative to implement the Continuing Care Strategy, setting the stage for implementation of more caregiver supports (Mihailescu, 2021). Access to this benefit allows care recipients to remain in their homes to age in place for a longer amount of time, which was anticipated to decrease healthcare spending overall (Mihailescu, 2021). O’Hara (2014) compared the caregiver benefit program in Nova Scotia with the Manitoba Caregiver Tax Credit through secondary data analysis and interviews with policy experts. It was reported that clients receiving the benefit in Nova Scotia are 56% less likely to be admitted to long term care facilities (O’Hara, 2014). Therefore, Saskatchewan’s current systems should focus on positive aging in the community, in addition to supporting those in care.
Strengths and Limitations

Due to the breadth of this study, a variety of strengths and limitations exist at different points, which are described in this section. Regarding study design, strengths and limitations of qualitative description (Sandelowski, 2000, 2010) and the online delivery of the survey are explored. The oversights that occurred in the collection of data are also described.

Qualitative Description

Qualitative description offers a straight description of the data that is typically organized chronologically by topic or relevance (Neergaard et al., 2009; Sandelowski, 2000), which was ideal for this thesis study as one of the main objectives was to determine what Saskatchewan caregivers prioritized for support in their role. However, qualitative description is regarded as one of the least theoretical qualitative approaches to qualitative research (Neergaard et al., 2009). Despite not being based in theory, qualitative description should be the method of choice when a description of a phenomenon is desired (Neergaard et al., 2009), as was the case in this thesis study. Therefore, the overall employment of the qualitative descriptive approach is a strength to this study’s design. With that being said, limitations to the use of qualitative description still persisted. For example, there is no clearly defined approach to qualitative description (Milne & Oberle, 2005). It has been previously iterated that novice researchers can be faced with challenges and uncertainties when undertaking a study with a qualitative descriptive design (Milne & Oberle, 2005). As such, there could have potentially been some issues with rigor in the analysis process, especially considering this was a student project. These issues were mitigated by regular meetings occurring between the student and the supervisor, as well as a preliminary review of the results by the student’s entire advisory committee.

Online Delivery

The online delivery of this study is a somewhat unconventional method of interaction in qualitative research but its use has been emerging in recent years (Carter et al., 2021; Horrell et al., 2015). Qualitative researchers have been increasingly turning to online platforms for data collection (Carter et al., 2021). Online data collection is particularly useful in research projects that seek to recruit participants in different geographical areas, as it eliminates the need for long-distance travel (Im & Chee, 2006), which was an applicable strength in this thesis study. Participants in this study did not have to travel to or host the student researcher and there were no incidental costs associated with participating in the research. Online data collection also is often
more convenient for participants, as they can participate during their free time (Carter et al., 2021). Specifically for caregivers, online participation can be inviting because they do not need to arrange accommodations for the care recipient or respite time, which can often stand in the way of in-person research (Hewson, 2014; Horrell et al., 2015). Ethical challenges exist with online data collection, such as with ensuring informed consent is understood and the potential for participants to become distressed (Carter et al., 2021). These challenges were mitigated in this study by providing the participants a consent form as the entry page to the survey and contact information for supportive services was provided at the beginning and end of the survey. Lastly, a limitation of the online delivery of the survey required participants to have access to a device to engage with the survey and also have the required technological literacy to complete an online survey.

Data Collection

Apart from the strengths and limitations to data collection from the online delivery of the survey, there were oversights that occurred when collecting demographic data. Two limitations regarding the collection of caregiver demographic data exist. The first is that caregiver gender was not collected. This omission was an oversight. Although assessing differences in caregiver gender was not the specific aim of the study, the data would have allowed for additional interesting analysis. Not collecting caregiver ethnicity also proved to be a limitation and oversight in the context of Saskatchewan’s high population of Indigenous Peoples. It has been recognized that previous research has largely ignored the experiences, unique challenges, and perspectives of Indigenous caregivers in Canada (Jewell et al., 2022). As stated in this thesis’ Land Acknowledgment, one caregiver expressed via Facebook direct messenger that they were disappointed in the lack of ability to clearly attach their recount of experiences to their Indigenous identity. In my Land Acknowledgment, I offer an apology for this oversight to the Indigenous Peoples of Saskatchewan for not affording them this opportunity to identify as Indigenous in the survey. In parallel with caregiver demographic data, two limitations exist in the collection of care recipient data. The first was that there was no clear avenue to report whether or not the care recipient was still living. Some participants chose to write in the open textbox that their care recipient was “deceased” without providing an age; however, this is an unreliable method to identify bereaved caregivers. As well, the survey tool did not allow for determining
the rate of multimorbidity, as some participants responded to the question regarding medical conditions for more than one care recipient.

**Study Implications**

Qualitative health research is a powerful method to inform and advance health systems at different levels (Kozleski, 2017). Sallee and Flood (2012) describe how findings from qualitative research can be bridged into future research, policy, and practice. Researchers can use findings to develop and answer key questions in future studies; practitioners can implement research on the ground; and policymakers can utilize findings to create effective policies (Sallee & Flood, 2012). Furthermore, educational programs are shaped based on best practice guidance, which can be derived from qualitative research (Johnson et al., 2020). As such, the Saskatchewan Caregiver Experience Study has implications for research, practice, education, and policy.

**Research**

Since this thesis study was exploratory and sought to map the caregiver experience in Saskatchewan, the findings can help to develop support services and interventions to facilitate meeting the needs that were reported by participants. Caregivers to older adults have previously iterated they have an interest in research engagement (Haase, Tompson, et al., 2021; Hall & Holtslander, 2022). Participants in this study also shared gratitude for having the opportunity to share the stories of their caregiver experience. Researchers should capitalize on this interest in research by co-creating solutions to improve the caregiver experience. Findings from this thesis study also suggest that more research is needed to examine how to amplify the positive aspects of the caregiver experience. The caregiver experience of Indigenous Peoples in Saskatchewan should be explored, as this population may have unique needs and priorities that require addressing as well.

**Practice**

Implications for healthcare practice largely revolve around recognizing caregivers for their value and contribution to the health of the individuals they provide care to. Previous literature has reported that it is challenging to engage with caregivers due to limited recognition of caregiver involvement in patient care by current healthcare systems (Mitnick et al., 2010; Semere et al., 2022; Vanderhout et al., 2022). Recognition of the caregiver experience by healthcare professionals is essential in planning services to support care recipients and caregivers in ways that are meaningful and effective. A systematic review by Mitnick et al. (2010) also
reported that recognizing the caregiver experience contributes to the positive aspects of caregiving and decreases rates of patient hospitalization and institutionalization due to the associated decrease in caregiver role strain and burden.

Caregivers in this thesis study indicated they want to feel valued by healthcare professionals and participants called for enhanced communication between healthcare professionals and caregivers. Semere et al. (2022) interviewed 15 physicians regarding their perspectives on caregivers in a qualitative study. Themes from their study with physicians overlap with findings from this study’s survey of caregivers themselves. Physicians recognized that they need to adapt appointment communication strategies to include caregivers, engage caregivers in patient care, and find ways to care for the caregiver in tandem with the care recipient (Semere et al., 2022). One physician participant in the study by Semere et al. (2022) stated, “If we care for our patients’ caregivers, that’s an indirect way of taking care of our patients” (p. 7). Another consideration in communication with caregivers is the caregiver’s level of health literacy. Health literacy is a combination of competencies and resources needed for people to access, understand, appraise, and apply information and services to make informed decisions regarding health (Levin-Zamir et al., 2019). Participants in this thesis study reported wanting greater clear and concise information about the care recipient’s condition. In a study by Kimzey et al. (2022), caregivers to persons living with dementia described developing health literacy competencies over time; however, they ended up “becoming the expert[s]” (p. 548) because of their tenacity in information-seeking from healthcare professionals. Therefore, explicit implications for practice include healthcare professionals effectively communicating with caregivers, considering the caregiver’s health literacy, working to enhance the caregiver’s health literacy, and recognizing that the caregiver’s well-being has a direct impact on the well-being of the care recipient.

**Education**

Despite the growing contribution of caregivers to the healthcare system, support for caregivers has not historically been a health system priority (Parmar et al., 2021). However, this thesis study highlights that in Saskatchewan, supporting caregivers and providing patient and caregiver-centred care must become a priority. A set of competencies for healthcare professionals to provide caregiver-centred care was developed in Alberta, Canada by Parmar et al. (2021) through stakeholder engagement. The competency domains for caregiver-centred care
included: (1) recognizing the caregiver role; (2) communicating with caregivers; (3) partnering with caregivers; (4) fostering resilience in caregivers; (5) navigating health and social systems and accessing resources; and (6) enhancing the culture and context of healthcare (Parmar et al., 2021). Within these competencies, many indicators of the competent provision of caregiver-centred care are seemingly missing from the healthcare landscape which caregivers in Saskatchewan access. Therefore, this thesis study highlights that either the implementation of either caregiver-centred care competencies identical to those of Parmar et al. (2021), or similar competencies adapted to the Saskatchewan context, should be implemented into the training of new healthcare professionals and continuing education of healthcare professionals in active practice.

Policy

Specific findings from this study can offer implications for policy. Leveraging informal care in place of institutional long term care has become a key strategy in maintaining healthcare system sustainability worldwide (Carstairs & Keon, 2009; Khayatzadeh-Mahani & Leslie, 2018). However, from the findings within this study, the Saskatchewan healthcare system could be placing more emphasis on aging in place and enhanced community care. In a brief review of existing Canadian literature and policy, there was found to be a paucity of current policies that enhance caregiver support at both provincial and federal levels. Currently, most governmental supports focus on providing assistance to those with care recipients in care homes, rather than positive aging in the community. This focus is contradictory to previous governmental efforts in the 2000s (Carstairs & Keon, 2009) that sought to enhance caregiver support. Therefore, current systems at provincial and federal levels should focus on positive aging in the community, in addition to supporting those in care. Findings from this study can be used to adapt policies to improve the support that caregivers to older adults receive in the community.
CHAPTER 6: CONCLUSION

The purpose of this thesis study was to describe the experiences and perspectives of caregivers in Saskatchewan and to identify the priority support needs of these caregivers. As the caregiver experience affects so many individuals within our province, this project has the potential to have an impact on future research, practice, education, and policy in Saskatchewan. Considering the essential role that caregivers play in providing care to older adults in the community, focused attention should be directed toward supporting these individuals in their caregiving role. In this study, Saskatchewan caregivers were given the opportunity through a survey to share the challenges and positive aspects of their caregiving role in addition to reporting their support needs. Positive and negative experiences often co-exist on the spectrum of caregiving (Toljamo et al., 2012), which can manifest as ambivalence towards the provision of care (Shim et al., 2012). By gathering the full spectrum of the caregiver experience in Saskatchewan, this study can help to inform how communities, governments, and our healthcare system can best support caregivers in their roles. Carers Canada (2021) states on their website that the question is not ‘if you will become a caregiver,’ but rather ‘when will you become a caregiver?’ As such, it is critical that systems move towards functioning in a manner that enhances the caregiver experience.
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<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver (informal / family)</td>
<td>“Caregiving is the process of helping another person who is unable to do for themselves in a ‘holistic’ (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotional skills, knowledge, time, and an emotional connection with the care recipient” (p. 15).</td>
<td>Hermanns and Mastel-Smith (2012)</td>
</tr>
<tr>
<td>Carer</td>
<td>Synonymous with “caregiver.”</td>
<td></td>
</tr>
<tr>
<td>Involvement in caregiving</td>
<td>The number of caregiving tasks performed and the amount of time the caregiver spends performing them.</td>
<td>Schott-Baer (1993)</td>
</tr>
<tr>
<td>Care recipient</td>
<td>“An adult with a chronic illness or disabling condition or an older person who needs ongoing assistance with everyday tasks to function on a daily basis.”</td>
<td>Family Caregiver Alliance (2021)</td>
</tr>
<tr>
<td>Loved one</td>
<td>Often used synonymously with care recipient in literature; however, this assumes that love is a factor within the caregiving exchange, which is not always the case. This report will use “care recipient” only.</td>
<td></td>
</tr>
<tr>
<td>Chronic disease</td>
<td>Diseases of long duration and slow progression, such as cardiovascular disease, cancers, chronic respiratory diseases, and diabetes.</td>
<td>World Health Organization (2014)</td>
</tr>
<tr>
<td>Chronic illness</td>
<td>The subjective experience of loss of health due to chronic disease, which includes mental illnesses.</td>
<td>Paterson (2001)</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
<td>Source</td>
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<tr>
<td>-------------------------</td>
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</tr>
<tr>
<td>Anticipatory grief</td>
<td>“Any grief occurring prior to a loss, as distinguished from the grief which occurs at or after a loss” (p. 4).</td>
<td>Aldrich (1974)</td>
</tr>
<tr>
<td>Complicated grief</td>
<td>“The failure to return to pre-loss levels of performance or states of emotional well-being. For a considerable minority of bereaved persons, emotional and behavioural disturbances persist and prevent the return to normal functioning” (p. 23).</td>
<td>Prigerson et al. (1995)</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>The caregiver’s emotional evaluation of the caregiving exchange, expressed as the extent to which the caregiver finds it challenging to care for the recipient. Encompasses both objective and subjective burden.</td>
<td>Montgomery and Borgatta (1989)</td>
</tr>
<tr>
<td>Objective burden</td>
<td>“The extent of disruptions or changes in various aspects of the caregiver’s life and household” (p. 458).</td>
<td>Montgomery and Borgatta (1989)</td>
</tr>
<tr>
<td>Subjective burden</td>
<td>“Reflects the caregiver’s stress and nervousness related to her or his situation and the extent to which the caregiver feels manipulated by the demands of the care receiver” (p. 458).</td>
<td>Montgomery and Borgatta (1989)</td>
</tr>
<tr>
<td>Caregiver stress</td>
<td>The feeling experienced by caregivers when they perceive the demands of caregiving have exceeded the personal and social resources of which they are able to mobilize.</td>
<td>Lazarus and Folkman (1984)</td>
</tr>
<tr>
<td>Caregiver satisfaction</td>
<td>The dimension of caregiving that represents subjectively perceived gains from desirable aspects of caregiving.</td>
<td>Lawton et al. (1989)</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
<td>Source</td>
</tr>
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<td>-------------------------------</td>
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</tr>
<tr>
<td>Financial strain</td>
<td>Conceptualized as financial distress that informal caregivers may experience due to caregiving duties and financial demands.</td>
<td>Lee and Zurlo (2014)</td>
</tr>
<tr>
<td>Hope</td>
<td>“Inner strength that [gives caregivers] the courage and ability to go through a difficult situation” (p. 289).</td>
<td>Holtslander et al. (2005)</td>
</tr>
<tr>
<td>Bereavement</td>
<td>“A state of loss, triggering a grief reaction that manifests in a set of behaviours known as mourning” (p. 44).</td>
<td>Buglass (2010)</td>
</tr>
<tr>
<td>Quality of life (QOL)</td>
<td>“An overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values” (p. 60).</td>
<td>Felce and Perry (1995)</td>
</tr>
<tr>
<td>Health-related quality of life (HRQL)</td>
<td>“Aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment” (p. 1384).</td>
<td>Ebrahim (1995)</td>
</tr>
<tr>
<td>Aging in place (Canadian definition)</td>
<td>“Having the health and social supports and services you need to live safely and independently in your home or your community for as long as you wish and are able.”</td>
<td>Government of Canada (2012)</td>
</tr>
<tr>
<td>Aging in place (WHO definition)</td>
<td>“Meeting the desire and ability of people, through the provision of appropriate services and assistance, to remain living relatively independently in the community in his or her current home or an appropriate level of housing. Aging in place is designed to prevent or delay more traumatic moves to a dependent facility, such as a nursing home” (p. 9).</td>
<td>World Health Organization (2004)</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
<td>Source</td>
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</tr>
<tr>
<td>Long term care</td>
<td>“A variety of services designed to meet a person’s health or personal care needs during a short or long period of time. These services help people live as independently and safely as possible when they can no longer perform everyday activities on their own.”</td>
<td>National Institute on Aging (2017)</td>
</tr>
<tr>
<td>Respite care</td>
<td>Described as both a service and an outcome: “as a service, it covers a spectrum of possibilities ranging from home-based care to day care, to short-term stay in a nursing home; as an outcome, it is often seen to provide relief for the family carer” (p. 1397).</td>
<td>Hanson et al. (1999)</td>
</tr>
<tr>
<td>Psychoeducation</td>
<td>“An intervention with systematic, structured, and didactic knowledge transfer for an illness and its treatment, integrating emotional and motivational aspects to enable patients to cope with the illness and to improve its treatment adherence and efficacy” (p. 239).</td>
<td>Ekhtiari et al. (2017)</td>
</tr>
</tbody>
</table>
### Table 1.2

**Examination of Motivations for Caregiving (Guberman et al., 1993) and Brief Summaries**

<table>
<thead>
<tr>
<th>Motivation for Assuming Caregiving Role</th>
<th>Brief Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental and filial love or feelings as well as emotional ties.</td>
<td>Individuals refer to their feelings of love and affection, derived from the ideology of family, to explain their decision to become a caregiver.</td>
</tr>
<tr>
<td>The inadequacy of institutional resources.</td>
<td>The absence of measures to ensure post-hospitalization follow-up and the pressure from professionals to compel families to take responsibility of their care recipients, despite this absence.</td>
</tr>
<tr>
<td>The need to help others.</td>
<td>Feelings, beliefs, or behaviours that go beyond affection or maternal and filial feelings. For those who cite this motive, helping others gives meaning to their life.</td>
</tr>
<tr>
<td>Feelings of obligation and duty.</td>
<td>Family ties are often characterized by a mixture of feelings of affection and obligation, the balance of which varies from one caregiver to another. In some situations, the balance tilts in favour of negative feelings towards the care recipient.</td>
</tr>
<tr>
<td>The pressures of the dependent person.</td>
<td>Some older adults reject informal care from their family members, despite needing assistance. This may lead to the placement of the older adult in long-term care, which can result in guilt in potential caregivers. Families are faced with the choice between continuing to hold responsibility for a task that has become increasingly heavy or go against the wishes expressed by their care recipient and place them in an assisted living setting.</td>
</tr>
<tr>
<td>The non-availability of other family members.</td>
<td>Occasionally, no one is available or willing to commit to caregiving, therefore some feel a responsibility to take charge. Reasons for unavailability may be distance from care recipient, the economic situation of potential caregiver, being preoccupied with children or work, or a tumultuous</td>
</tr>
</tbody>
</table>
past relationship with the care recipient. Some also may just want to place the care recipient in an institution, while others feel a responsibility to act as a caregiver in the community.

<p>| Anti-institution sentiments. | Some see institutions (long-term care, assisted living) as dehumanizing, or as having an absence of love and care. These individuals have feelings of guilt for placing their care recipient in an institution, therefore they assume a caregiving role. |
| The modalities of the assumption of responsibility. | Some count on the help of other family members and their concrete involvement in care. For example, bringing the care recipient to appointments. (Also see <em>Types of Caregivers</em>) |
| Religious feelings. | Caregivers are motivated by their faith and derive moral values from their beliefs. From these beliefs, they feel a sense of duty to the care recipient. |
| The personal arrangements of the caregiver. | Individuals are motivated by their availability and personal qualities (resourceful, responsible, prepared for a challenge) to become caregivers. |
| Hope for healing. | The motivation to become a caregiver is driven by the hope of seeing the care recipient's state of health improve. |
| The state of health of the dependent person. | The relationship between the care recipient’s current degree of autonomy and the caregiver’s motivation to assist them based on that. |
| Family tradition. | Adult children taking care of their aging parents because their children will also take care of them one day. |</p>
<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Place of Study</th>
<th>Study Design</th>
<th>Sample Size</th>
<th>% Female</th>
<th>Mean Age (CG)</th>
<th>Mean Age (CR)</th>
<th>CR Condition</th>
<th>Relationship to CR</th>
<th>Method of Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aoun et al. (2015)</td>
<td>Australia</td>
<td>MM</td>
<td>233</td>
<td>70.4</td>
<td>62.1</td>
<td>70.3</td>
<td>Cancer</td>
<td>Spouse (n=157) Adult child (n=52) Sibling (n=5) Parent (n=4) Other (n=15)</td>
<td>Survey; interviews</td>
</tr>
<tr>
<td>Aoun et al. (2017)</td>
<td>Australia</td>
<td>MM</td>
<td>24</td>
<td>75</td>
<td>63.8</td>
<td>62.8</td>
<td>Motor neurone disease</td>
<td>Spouse (n=19) Adult child (n=1) Sibling (n=1) Parent (n=3)</td>
<td>Survey; interviews</td>
</tr>
<tr>
<td>Bauer et al. (2019)</td>
<td>Australia</td>
<td>MM</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>Dementia</td>
<td>NR</td>
<td>Focus groups; survey</td>
</tr>
<tr>
<td>Bressan et al. (2020)</td>
<td>N/A</td>
<td>SR</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Dementia</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Charles et al. (2017)</td>
<td>Canada</td>
<td>QL</td>
<td>76</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>Non-specific</td>
<td>NR</td>
<td>Conference workshop</td>
</tr>
<tr>
<td>Condon et al. (2019)</td>
<td>UK</td>
<td>MM</td>
<td>16</td>
<td>75</td>
<td>57.5</td>
<td>NR</td>
<td>Non-specific</td>
<td>Spouse (n=8) Other (n=8)</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Dal Bello-Haas et al. (2014)</td>
<td>Canada</td>
<td>MM</td>
<td>151</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>Dementia</td>
<td>NR</td>
<td>Meetings; questionnaires</td>
</tr>
<tr>
<td>Doherty et al. (2016)</td>
<td>N/A</td>
<td>SR</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Heart failure</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Dovi et al. (2020)</td>
<td>Belgium</td>
<td>QL</td>
<td>14</td>
<td>71.4</td>
<td>74</td>
<td>80</td>
<td>Dementia</td>
<td>Spouse (n=14)</td>
<td>Psychoeducational intervention</td>
</tr>
<tr>
<td>El Masry et al. (2013)</td>
<td>Australia</td>
<td>QL</td>
<td>20</td>
<td>80</td>
<td>NR</td>
<td>NR</td>
<td>Stroke</td>
<td>Spouse (n=15) Adult child (n=2) Sibling (n=3)</td>
<td>Interviews</td>
</tr>
<tr>
<td>Elliott et al. (2017)</td>
<td>Australia</td>
<td>MM</td>
<td>36</td>
<td>75</td>
<td>NR</td>
<td>NR</td>
<td>Dementia</td>
<td>Spouse (n=23) Adult child (n=7) Sibling (n=2) Other (n=4)</td>
<td>Conference workshop</td>
</tr>
<tr>
<td>Grant and Graven (2019)</td>
<td>USA</td>
<td>QL</td>
<td>530</td>
<td>49.1</td>
<td>41.4</td>
<td>54.3</td>
<td>Heart failure</td>
<td>Spouse (n=238) Adult child (n=108) Friend (n=34)</td>
<td>Online survey</td>
</tr>
<tr>
<td>Author, Year</td>
<td>Place of Study</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>% Female</td>
<td>Mean Age (CG)</td>
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<td>CR Condition</td>
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<td>Method of Interaction</td>
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<td>----------------------------------------</td>
</tr>
<tr>
<td>Grassel et al.</td>
<td>Germany</td>
<td>MM</td>
<td>404</td>
<td>73.3</td>
<td>61.3</td>
<td>78.8</td>
<td>Dementia</td>
<td>Spouse (n=177); Adult child (n=198); Other (n=29)</td>
<td>Survey; questionnaire</td>
</tr>
<tr>
<td>Halkett et al.</td>
<td>Australia</td>
<td>QL</td>
<td>20</td>
<td>95</td>
<td>56</td>
<td>NR</td>
<td>Cancer</td>
<td>Spouse (n=16); Adult child (n=1); Sibling (n=1); Parent (n=1)</td>
<td>Interviews</td>
</tr>
<tr>
<td>Hirakawa et al.</td>
<td>Japan</td>
<td>QN</td>
<td>475</td>
<td>77.1</td>
<td>64.9</td>
<td>81.2</td>
<td>Non-specific</td>
<td>Spouse (n=205); Adult child (n=235); Other (n=29)</td>
<td>Questionnaire</td>
</tr>
<tr>
<td>Katbamna et al.</td>
<td>UK</td>
<td>QL</td>
<td>18</td>
<td>77.8</td>
<td>NR</td>
<td>NR</td>
<td>Stroke</td>
<td>Spouse (n=16); Adult child (n=2)</td>
<td>Serial interviews</td>
</tr>
<tr>
<td>Keogh et al.</td>
<td>Ireland</td>
<td>QL</td>
<td>28</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>Dementia</td>
<td>Spouse (n=42); Parent (n=7); Other (n=10)</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Lambert et al.</td>
<td>Canada</td>
<td>MM</td>
<td>61</td>
<td>78.7</td>
<td>NR</td>
<td>NR</td>
<td>Cancer</td>
<td>Spouse (n=5); Adult child (n=11); Other (n=3)</td>
<td>Survey</td>
</tr>
<tr>
<td>Lamech et al.</td>
<td>India</td>
<td>QL</td>
<td>19</td>
<td>57.9</td>
<td>51.6</td>
<td>NR</td>
<td>Dementia</td>
<td>Spouse (n=5); Adult child (n=11); Other (n=3)</td>
<td>Focus group; interviews</td>
</tr>
<tr>
<td>Lamontagne et al.</td>
<td>Canada</td>
<td>QL</td>
<td>31</td>
<td>58.8</td>
<td>74.2</td>
<td>NR</td>
<td>Stroke</td>
<td>Spouse (n=18); Adult child (n=7); Sibling (n=1); Other (n=5)</td>
<td>Focus group</td>
</tr>
<tr>
<td>Leslie et al.</td>
<td>Canada</td>
<td>MM</td>
<td>25</td>
<td>84</td>
<td>NR</td>
<td>NR</td>
<td>Non-specific</td>
<td>Spouse (n=5)</td>
<td>Focus group</td>
</tr>
<tr>
<td>Lutz et al.</td>
<td>USA</td>
<td>QL</td>
<td>40</td>
<td>72.5</td>
<td>60.6</td>
<td>68.5</td>
<td>Stroke</td>
<td>Spouse (n=27); Adult child (n=12); Parent (n=1)</td>
<td>Interviews</td>
</tr>
<tr>
<td>Mahomed and Pretorius</td>
<td>South Africa</td>
<td>QL</td>
<td>11</td>
<td>0</td>
<td>61.2</td>
<td>NR</td>
<td>Dementia</td>
<td>Spouse (n=5); Adult child (n=6)</td>
<td>Interviews</td>
</tr>
<tr>
<td>Novais et al.</td>
<td>France</td>
<td>QN</td>
<td>68</td>
<td>67.5</td>
<td>69.1</td>
<td>80</td>
<td>Neurocognitive disorders</td>
<td>Spouse (n=43); Adult child (n=20); Other (n=5)</td>
<td>Questionnaires</td>
</tr>
<tr>
<td>Author, Year</td>
<td>Place of Study</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>% Female</td>
<td>Mean Age (CG)</td>
<td>Mean Age (CR)</td>
<td>CR Condition</td>
<td>Relationship to CR</td>
<td>Method of Interaction</td>
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<tr>
<td>Oliveira, Zarit, et al. (2019)</td>
<td>UK</td>
<td>QL</td>
<td>27</td>
<td>88.9</td>
<td>66.8</td>
<td>NR</td>
<td>Dementia</td>
<td>Spouse (n=20) Other (n=7)</td>
<td>Focus group</td>
</tr>
<tr>
<td>Oliveira et al. (2020)</td>
<td>UK</td>
<td>QL</td>
<td>150</td>
<td>65</td>
<td>72.2</td>
<td>NR</td>
<td>Dementia</td>
<td>Spouse (n=120) Other (n=30)</td>
<td>Questionnaire</td>
</tr>
<tr>
<td>Robinson et al. (2012)</td>
<td>Canada</td>
<td>MM</td>
<td>23</td>
<td>80</td>
<td>NR</td>
<td>NR</td>
<td>Non-specific</td>
<td>Spouse (n=11) Adult child (n=10) Sibling (n=1) Friend (n=1)</td>
<td>Questionnaire; interviews</td>
</tr>
<tr>
<td>Seddon et al. (2004)</td>
<td>UK</td>
<td>MM</td>
<td>46</td>
<td>NR</td>
<td>51</td>
<td>NR</td>
<td>Non-specific</td>
<td>Spouse (n=8) Adult child (n=35) Other (n=3)</td>
<td>Interviews; survey</td>
</tr>
<tr>
<td>Sinfield et al. (2012)</td>
<td>UK</td>
<td>QL</td>
<td>34</td>
<td>100</td>
<td>NR</td>
<td>NR</td>
<td>Cancer (prostate)</td>
<td>NR</td>
<td>Focus group; interviews</td>
</tr>
<tr>
<td>Sverre Vigeland et al. (2016)</td>
<td>Norway</td>
<td>QL</td>
<td>25</td>
<td>72</td>
<td>NR</td>
<td>NR</td>
<td>Motor neurone disease</td>
<td>NR</td>
<td>Interviews</td>
</tr>
<tr>
<td>Teahan et al. (2021)</td>
<td>Ireland</td>
<td>QL</td>
<td>17</td>
<td>70.6</td>
<td>NR</td>
<td>NR</td>
<td>Dementia</td>
<td>Spouse (n=10) Adult child (n=6) Other (n=1)</td>
<td>Focus group</td>
</tr>
<tr>
<td>Thomas et al. (2021)</td>
<td>USA</td>
<td>QL</td>
<td>15</td>
<td>53.3</td>
<td>65</td>
<td>NR</td>
<td>Cancer</td>
<td>Spouse (n=14) Adult child (n=1)</td>
<td>Focus group</td>
</tr>
<tr>
<td>Wingham et al. (2015)</td>
<td>UK</td>
<td>QL</td>
<td>26</td>
<td>73</td>
<td>66</td>
<td>NR</td>
<td>Heart failure</td>
<td>Spouse (n=24) Adult child (n=2)</td>
<td>Interviews; focus group</td>
</tr>
</tbody>
</table>

**Legend:**

- **CG** = Caregiver
- **CR** = Care recipient
- **NR** = Not reported
- **QN** = quantitative
- **QL** = qualitative
- **MM** = mixed methods
- **SR** = systematic review

**Note:** Adapted from “Caregivers to older adults require support: A scoping review of their priorities,” by S. Hall, N. Rohatinsky, L. Holtslander, and S. Peacock, 2022, *Health and Social Care in the Community, 30*(6), pp. e3789-e3809 ([https://doi.org/10.1111/hsc.14071](https://doi.org/10.1111/hsc.14071)). Copyright 2022 by John Wiley & Sons Ltd. Reprinted with permission.
### Table 2.2

**Study Aims, Themes, and Priorities Identified**

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Place of Study</th>
<th>CR Condition</th>
<th>Aim of Study</th>
<th>Themes</th>
<th>Priorities Identified</th>
</tr>
</thead>
</table>
| Aoun et al. (2015) | Australia    | Cancer             | Investigate the impact of using the CSNAT to identify support needs in end-of-life home caregiving. | N/A                                                             | 1) Knowing what to expect in the future.  
2) Having time to yourself in the day.  
3) Dealing with your feelings and worries.  
4) Understanding your relative's illness |
2) CSNAT practicality and usefulness.  
3) Validation of the caregiver role and empowerment.  
4) Reassurance of support.            | 1) Knowing what to expect in the future.  
2) Knowing who to contact if concerned.  
3) Having equipment to assist in care.  
4) Dealing with feelings and worries.  
5) Having time for themselves during the daytime. |
| Bauer et al. (2019) | Australia    | Dementia            | Identify and prioritize service and support needs of people with dementia and their careers. | N/A                                                             | 1) Improving early diagnosis of dementia so that services and appropriate information can be accessed.  
2) More training for health professionals to help them understand the experience of living with dementia, what it is like to be a carer and the importance of sharing information about current best practice.  
3) More community awareness and education about living with dementia to reduce stigma in the community and increase awareness of the support needs of carers  
4) More support for carers and someone to talk to and share experiences about fears, loneliness, struggles, health and well-being and care strategies. |
| Bressan et al. (2020) | N/A            | Dementia            | Identify and synthesize literature on the needs of family caregivers of people with dementia. | 1) Being supported.  
2) Receiving accessible and personalised information.  
3) Being trained and educated to care for their beloved with dementia.  
4) Finding a balance.              | See themes.                                                                                     |
<table>
<thead>
<tr>
<th>Author, Year</th>
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<th>Themes</th>
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</thead>
<tbody>
<tr>
<td>Charles et al. (2017)</td>
<td>Canada</td>
<td>Non-specific</td>
<td>Describe the experiences and challenges of family caregivers with complex needs.</td>
<td>1) Managing a multitude of tasks which can compromise caregivers' ability to address personal needs. 2) Changing roles and obligations, and the shift away from traditional family structures which is having an impact on caregiving. 3) The significant financial and occupational impact of caregiving</td>
<td>1) Assisting caregivers in self-identifying and seeking support. 2) Formalizing caregiver supports. 3) Centralizing resources. 4) Making system navigators available. 5) Preparing the next generation for caregiving.</td>
</tr>
<tr>
<td>Condon et al. (2019)</td>
<td>UK</td>
<td>Non-specific</td>
<td>Identify key components of a support intervention.</td>
<td>1) Changes in relationships, roles, and dynamics. 2) Emotional impact and acceptance. 3) Drawing on inner resources. 4) Looking for information, solutions, and explanations. 5) Support from others</td>
<td>1) Acknowledging &quot;normal&quot; emotions. 2) Education about the effects of a stroke. 3) Reactions to loss and adjustment. 4) Recognizing signs and symptoms of not coping. 5) Knowing how and when to access practical and emotional support. 6) Strategies for taking care of own health. 7) Dealing with difficult emotions. 8) Problem solving skills</td>
</tr>
<tr>
<td>Dal Bello-Haas et al. (2014)</td>
<td>Canada</td>
<td>Dementia</td>
<td>Discuss perceived needs related to providing rural dementia care.</td>
<td>1) Perceived lack of care, inadequate care or inappropriate. 2) Family physician or other HCP minimized the problems. 3) Wait times or amount of time to diagnosis. 4) Lack of diagnosis</td>
<td>1) Increased availability and types of services, care facilities, and programs. 2) Increased access to primary care providers, specialists, and rehabilitation professionals to address wait times for diagnosis and management. 3) Continuing education related to recognising signs and symptoms of AD and other dementias, and the diagnosis and management of people with dementia.</td>
</tr>
<tr>
<td>Doherty et al. (2016)</td>
<td>N/A</td>
<td>Heart failure</td>
<td>Explore evidence on palliative care needs of carers of people with heart failure.</td>
<td>1) Psychosocial support for a sense of normalcy. 2) Support with daily living. 3) Support navigating the healthcare system</td>
<td>See themes.</td>
</tr>
<tr>
<td>Dovi et al. (2020)</td>
<td>Belgium</td>
<td>Dementia</td>
<td>Explore the lived experiences of spousal caregivers before and after participation in a psychoeducational intervention.</td>
<td>1) Obtaining information about dementia. 2) Learning tools to manage symptoms of dementia. 3) Interacting with peers.</td>
<td>1) Obtaining information. 2) Learning tools to manage symptoms of dementia. 3) Peer interaction. 4) Respite.</td>
</tr>
<tr>
<td>Author, Year</td>
<td>Place of Study</td>
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<td>Priorities Identified</td>
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</tr>
<tr>
<td>El Masry et al. (2013)</td>
<td>Australia</td>
<td>Stroke</td>
<td>Explore the psychosocial aspects of the experiences, concerns, and needs of caregivers of persons following stroke.</td>
<td>1) Relationships and support. 2) Caregiver factors. 3) Stroke survivor factors. 4) External stressors. 5) Positive outcomes</td>
<td>1) Independence. 2) Stroke education and knowledge. 3) Improved access to and quality of formal and informal support.</td>
</tr>
<tr>
<td>Elliott et al. (2017)</td>
<td>Australia</td>
<td>Dementia</td>
<td>Explore congruence between support needs and support services for carers of people with dementia living in the community.</td>
<td>1) Quality support for carers and the person with dementia. 2) Carers want adaptive, tailored, and flexible organizations. 3) Carers want to develop the workforce</td>
<td>1) More support (support for the care environment, support for caring for the person with dementia, support for carers to cope personally). 2) Information about dementia and services. 3) Better access to services</td>
</tr>
<tr>
<td>Grant and Graven (2019)</td>
<td>USA</td>
<td>Heart failure</td>
<td>Identify high priority problems experienced by caregivers when providing care to individuals with heart failure at home.</td>
<td>1) Performing multifaceted activities and roles that evolve around daily HF demands. 2) Maintaining caregiver physical, emotional, social, and financial well-being. 3) Providing unending care</td>
<td>1) Maintaining self-care activities, ADLs and IADLs. 2) Maintaining physical, emotional, social, and financial well-being. 3) Assistance in caregiving responsibilities.</td>
</tr>
<tr>
<td>Grassel et al. (2010)</td>
<td>Germany</td>
<td>Dementia</td>
<td>Determine what influences caregivers to utilise support groups and what caregivers want from support groups.</td>
<td>N/A</td>
<td>1) Exchanging caregiving experiences. 2) Information-seeking. 3) Group communication with willingness to listen.</td>
</tr>
<tr>
<td>Halkett et al. (2020)</td>
<td>Australia</td>
<td>Cancer</td>
<td>Explore the lived experiences of carers of patients diagnosed with head and neck cancer.</td>
<td>1) Silent suffering. 2) Gamut of emotions. 3) Causal attribution. 4) Changing priorities. 5) Gaining support. 6) Coping</td>
<td>1) Being available for care recipient. 2) Taking an active role in managing disease process.</td>
</tr>
<tr>
<td>Hirakawa et al. (2011)</td>
<td>Japan</td>
<td>Non-specific</td>
<td>Explore the priority information needs and sources of caregivers.</td>
<td>N/A</td>
<td>1) Caregivers want to learn first aid. 2) Information on formal care services. 3) Information on food and nutrition</td>
</tr>
<tr>
<td>Kambam et al. (2017)</td>
<td>UK</td>
<td>Stroke</td>
<td>Explore factors contributing to stress in</td>
<td>1) Inpatient care and formal support. 2) Discharge home and formal support.</td>
<td>1) Support is needed for caregivers.</td>
</tr>
<tr>
<td>Author, Year</td>
<td>Place of Study</td>
<td>CR Condition</td>
<td>Aim of Study</td>
<td>Themes</td>
<td>Priorities Identified</td>
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</table>
| White and British Indian carers of stroke survivors and the strategies they use to overcome the difficulties of providing care. | 3) Competent to care.  
4) Long-term outcome.  
5) Dynamics of caregiving.  
6) Anxiety linked to financial pressures.  
7) Coping strategies and resilience.  
8) Managing uncertainty. | 2) Information regarding discharge procedures, care worker tasks, and financial support.  
3) Culturally appropriate needs and support must be identified. |
| Keogh et al. (2021) | Ireland        | Dementia     | Highlight the voices and experiences of people with dementia and their family carers to influence legislation on home care. | See priorities identified. | 1) Home care.  
2) Respite services.  
3) Psychosocial supports.  
4) Financial supports. |
| Lambert et al. (2019) | Canada        | Cancer       | Engage caregivers and other stakeholders to identify priority topics for caregiver research in cancer care. | 1) Impact of cancer.  
2) Support programs.  
3) Vulnerable caregivers.  
4) Technology.  
5) Role in health care.  
6) Caregiver-centered care.  
7) Knowledge translation.  
8) Environmental scan.  
9) Financial cost of caregiving.  
10) Policy. | 1) Home care interventions.  
2) Caregiver perspectives on how support and information can best be provided to them by HCPs.  
3) Identifying caregivers at greatest risk for burden.  
4) Financial impacts and direct costs.  
5) Resources about death and dying. |
| Lamech et al. (2019) | India          | Dementia     | Explore the needs and challenges of family caregivers in Chennai, India. | 1) Low knowledge and understanding of dementia.  
2) Social challenges.  
3) Emotional strain of caregiving.  
4) Challenges in providing and managing care.  
5) Building health system capacity.  
6) Financial support and cost-effective services. | 1) Need for trained staff and person-centred care.  
2) Need for dementia specific healthcare facilities.  
3) Financial support and cost-effective services. |
| Lamontagne et al. (2019) | Canada        | Stroke       | Document experiences and perceptions of people with stroke and their caregivers about the existing continuum of care in Quebec, Canada. | 1) Accessibility of care.  
2) Appropriateness of care.  
3) Expertise of the healthcare workers.  
4) Continuity of care. | 1) Better access to services.  
2) Better access to information about available resources and transportation.  
3) Accommodations for care recipients.  
4) Better resources to improve the continuity of services from hospital to community. |
<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Place of Study</th>
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<th>Aim of Study</th>
<th>Themes</th>
<th>Priorities Identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leslie et al. (2021)</td>
<td>Canada</td>
<td>Non-specific</td>
<td>Address the feasibility and effectiveness of technology-based interventions to support caregivers to older adults.</td>
<td>1) Personal care quality and communication goals. 2) External care quality and communication goals. 3) Dimensions of external communications quality. 4) ICT for high quality communications</td>
<td>1) Better communication. 2) Socialization outside the home. 3) Forming human connections that make caregiving more sustainable.</td>
</tr>
<tr>
<td>Lutz et al. (2017)</td>
<td>USA</td>
<td>Stroke</td>
<td>Develop a theoretical framework for improving stroke caregiver readiness that is grounded in the experiences of stroke family caregivers.</td>
<td>N/A</td>
<td>1) Identifying and activating resources. 2) Readying the home environment. 3) Skills training to meet day-to-day needs. 4) Training for case management role. 5) Planning for self-care to enhance sustainability.</td>
</tr>
<tr>
<td>Mahomed and Pretorius (2021)</td>
<td>South Africa</td>
<td>Dementia</td>
<td>Explore the needs of male caregivers of people with Alzheimer’s disease.</td>
<td>1) Awareness, knowledge, and education. 2) Caregivers who don’t use services. 3) Caregivers who use services. 4) Service needs identified by male caregivers</td>
<td>1) Respite care. 2) Affordable, quality facilities. 3) The need for psychoeducation.</td>
</tr>
<tr>
<td>Novais et al. (2018)</td>
<td>France</td>
<td>Neurocognitive disorders</td>
<td>Gather opinions and gain consensus on caregivers’ priorities and identify common needs among informal caregivers of people with neurocognitive disorders.</td>
<td>N/A</td>
<td>1) Interventions focused on disease and treatment information. 2) Psychoeducational interventions.</td>
</tr>
<tr>
<td>Oliveira, Zarit, et al. (2019)</td>
<td>UK</td>
<td>Dementia</td>
<td>Explore the views of carers about self-care behaviour.</td>
<td>1) Information and awareness. 2) Service organization and coordination. 3) Continuity of care. 4) Relationships and feelings. 5) Prioritizing own needs. 6) Financial strain</td>
<td>1) Education and awareness. 2) Respite breaks. 3) Continuity of support. 4) Staff attitudes towards dementia. 5) Service organization and coordination.</td>
</tr>
<tr>
<td>Oliveira et al. (2020)</td>
<td>UK</td>
<td>Dementia</td>
<td>Explore what older family carers of people with dementia believe would most improve their quality of life.</td>
<td>1) More opportunities to enjoy life outside of caregiving. 2) Carer/dementia friendly health and social care systems. 3) Financial support</td>
<td>1) Respite. 2) Accessing health and social services that are dementia friendly. 3) Economic support.</td>
</tr>
<tr>
<td>Author, Year</td>
<td>Place of Study</td>
<td>CR Condition</td>
<td>Aim of Study</td>
<td>Themes</td>
<td>Priorities Identified</td>
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</table>
| Robinson et al. (2012) | Canada         | Non-specific         | Understand ways in which we can support the well-being of caregivers of rural palliative patients. | 1) The need to be(come) a palliative caregiver.  
2) The need to be skilled and know more.  
3) The need to navigate competing wishes, needs, demands, and priorities.  
4) The need for “an extra pair of hands.”                                                                 |                                                                                                         |
2) Flexible delivery of health and social care services.  
3) Reliability of services.  
4) Range and scope of services.  
5) Links with employers (supporting carers in employment).                                                                 |
| Sinfield et al. (2012) | UK             | Cancer (prostate)    | Explore the needs of carers of men with prostate cancer and to identify barriers and enablers to meeting these needs. | 1) Information.  
2) Emotional support.  
3) Practical support.  
4) Helping facilitate effective medical care for the patient                                                                 | 1) Better signposting to information and sources of support.  
2) Assessment of carer’s needs.                                                                                   |
| Sverre Vigeland et al. (2016) | Norway Motor neurone disease | Understand the complexities of caring for a person with motor neurone disease. | 1) Immediate care work.  
2) Seeking information and clarity.  
3) Managing competing obligations.  
4) Maintaining normality.  
5) Managing external resources and assistance                                                                 | See themes.                                                                                          |
| Teahan et al. (2021)  | Ireland        | Dementia             | Identify the range of challenges experienced by family carers of people with dementia and to ascertain their preferences for various supports and services that address those challenges. | 1) Needing a break  
2) Social isolation  
3) Changing relationships                                                                                                                                       | Personal-Level Supports:  
1) Daycare  
2) Family care support groups  
3) Short-term respite  
4) Long-break respite  
5) Social activities.  
Social Challenge Supports:  
1) Non-means tested carer’s allowance  
2) Legal recognition  
3) Carer’s support grant  
4) Monthly wage  
5) Community awareness programs |
<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Place of Study</th>
<th>CR Condition</th>
<th>Aim of Study</th>
<th>Themes</th>
<th>Priorities Identified</th>
</tr>
</thead>
</table>
| Thomas et al.     | USA            | Cancer       | Summarize caregivers’ recommendations for research and clinical priorities in cancer caregiving. | 1) Information and training on cancer diagnosis and treatment.  
2) Recognition from clinicians and inclusion within the medical setting.  
3) Assistance with understanding how the cancer clinic functions so they can effectively navigate care delivery | 1) Training and information about cancer and treatment.  
2) Caregiver integration into patient’s healthcare delivery.  
3) Assistance with navigating the healthcare system.  
4) Focus on caregiver health and well-being.  
5) Policy reform to address caregivers. |
| Wingham et al.    | UK             | Heart failure| Identify the needs of caregivers supporting a person with heart failure and to inform the development of a caregiver resource to be used as part of a home-based self-management programme. | 1) Providing support  
2) Becoming a caregiver  
3) Getting help | 1) Need for support in the management of heart failure  
2) Assistance in developing skills when transitioning to becoming a caregiver  
3) Social support, and voluntary and formal services |

**Legend:**  
CG = Caregiver  
CR = Care recipient  
ADLs = Activities of Daily Living  
IADLs = Instrumental ADLs

**Note:** Adapted from “Caregivers to older adults require support: A scoping review of their priorities,” by S. Hall, N. Rohatinsky, L. Holtslander, and S. Peacock, 2022, *Health and Social Care in the Community, 30*(6), pp. e3789-e3809 ([https://doi.org/10.1111/hsc.14071](https://doi.org/10.1111/hsc.14071)). Copyright 2022 by John Wiley & Sons Ltd. Reprinted with permission.
Table 2.3  
*Content Analysis NVivo 12 Codebook*

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<tr>
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<tr>
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<td>Improving diagnosis process</td>
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<td>Policy reform to address caregivers</td>
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<td>End-of-life resources</td>
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<td>Support in employment</td>
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### Table 3.1

*Saskatchewan’s Top 15 Population Centres (Statistics Canada, 2018)*

<table>
<thead>
<tr>
<th>Geographic name</th>
<th>Population centre size group</th>
<th>Population, 2016</th>
</tr>
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<tr>
<td>Saskatoon</td>
<td>Large urban</td>
<td>245181</td>
</tr>
<tr>
<td>Regina</td>
<td>Large urban</td>
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<tr>
<td>Prince Albert</td>
<td>Medium</td>
<td>35102</td>
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<td>Moose Jaw</td>
<td>Medium</td>
<td>32724</td>
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<tr>
<td>Yorkton</td>
<td>Small</td>
<td>16041</td>
</tr>
<tr>
<td>Swift Current</td>
<td>Small</td>
<td>16022</td>
</tr>
<tr>
<td>North Battleford</td>
<td>Small</td>
<td>13567</td>
</tr>
<tr>
<td>Estevan</td>
<td>Small</td>
<td>11258</td>
</tr>
<tr>
<td>Warman</td>
<td>Small</td>
<td>10961</td>
</tr>
<tr>
<td>Weyburn</td>
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<td>10679</td>
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<tr>
<td>Martensville</td>
<td>Small</td>
<td>9533</td>
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<tr>
<td>Melfort</td>
<td>Small</td>
<td>5778</td>
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<tr>
<td>La Ronge</td>
<td>Small</td>
<td>5671</td>
</tr>
<tr>
<td>Meadow Lake</td>
<td>Small</td>
<td>5266</td>
</tr>
<tr>
<td>Humboldt</td>
<td>Small</td>
<td>4872</td>
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**Note:** Lloydminster SK/AB was excluded from list and inclusion criteria due to the interprovincial border.
Table 3.2

*Online Qualitative Survey Blueprint*

<table>
<thead>
<tr>
<th>Question</th>
<th>Rationale and Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please enter the first three digits of your postal code (e.g., S7H).</td>
<td>This was used to later generate a map with pinpoints of the general areas where participants are from for the final results and data presentation. See Figure 4.2</td>
</tr>
<tr>
<td>Do you consider yourself to live in an urban or rural setting?</td>
<td>For clarification from the participant on which setting they consider themselves to live in.</td>
</tr>
<tr>
<td>a) Urban (large)</td>
<td></td>
</tr>
<tr>
<td>b) Urban (small/medium)</td>
<td></td>
</tr>
<tr>
<td>c) Rural</td>
<td></td>
</tr>
<tr>
<td>What is your age?</td>
<td>Participant demographic data.</td>
</tr>
<tr>
<td>What is the age of your care recipient?</td>
<td>Participant demographic data.</td>
</tr>
<tr>
<td><em>Note: Your care recipient is the person you are a caregiver to.</em></td>
<td></td>
</tr>
<tr>
<td>How many years have you been in your caregiving role?</td>
<td>Participant demographic data.</td>
</tr>
<tr>
<td>Did you receive any form of training for your caregiving role?</td>
<td>Participant demographic data.</td>
</tr>
<tr>
<td>If you did receive training, what kind of training did you receive?</td>
<td>To identify what training caregivers can access within the province, or attribute to advancing their caregiving abilities.</td>
</tr>
<tr>
<td>[open text box]</td>
<td></td>
</tr>
<tr>
<td>What is your relationship to your care recipient?</td>
<td>The caregiver-care recipient relationship can contribute to many factors, such as the levels of burden or strain (Hong &amp; Kim, 2008; Juntunen et al., 2018) and overall perception of the caregiving role (Kwak et al., 2012). For example, spousal caregivers are at a heightened risk for adverse health effects and burden care (Killner &amp; Soundy, 2018; Pakenham &amp; Samios, 2013).</td>
</tr>
<tr>
<td>a) Caring for a spouse</td>
<td></td>
</tr>
<tr>
<td>b) Caring for a parent</td>
<td></td>
</tr>
<tr>
<td>c) Caring for a sibling</td>
<td></td>
</tr>
<tr>
<td>d) Caring for a friend or neighbour</td>
<td></td>
</tr>
<tr>
<td>e) Other: [open text box]</td>
<td></td>
</tr>
<tr>
<td>What is your care recipient’s medical condition?</td>
<td>As identified in Chapter 2, the priorities of caregivers differ based on the care recipient’s conditions.</td>
</tr>
<tr>
<td>a) Dementia / Alzheimer’s</td>
<td></td>
</tr>
<tr>
<td>b) Neurological disorder (e.g., multiple sclerosis)</td>
<td></td>
</tr>
<tr>
<td>c) Heart, kidney, or lung condition</td>
<td></td>
</tr>
<tr>
<td>d) Cancer (any type)</td>
<td></td>
</tr>
</tbody>
</table>
| e) Prefer not to disclose                                              |                                                                                                 }

172
<table>
<thead>
<tr>
<th><strong>Question</strong></th>
<th><strong>Rationale and Justification</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>f) Other: [open text box]</td>
<td></td>
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<tr>
<td><em>For the next three questions, please provide a short response in the text box provided.</em></td>
<td></td>
</tr>
<tr>
<td>What do you find is most challenging about being a caregiver? [open text box]</td>
<td>To address the first research question: “What are the challenges and positive aspects of the caregiver experience in Saskatchewan?”</td>
</tr>
<tr>
<td>What do you find is positive about your caregiving role? [open text box]</td>
<td>To address the first research question: “What are the challenges and positive aspects of the caregiver experience in Saskatchewan?”</td>
</tr>
<tr>
<td>What do you think is most important for support in your caregiving role? In other words, what are your top priorities for support? [open text box]</td>
<td>To address the second research question: “What do caregivers to older adults in Saskatchewan identify as priorities for support?”</td>
</tr>
<tr>
<td>Is there anything else you would like to add about the experiences, perspectives, and priority support needs of caregivers in Saskatchewan? [open text box]</td>
<td>This is to allow participants to include anything else that is an experience, perspective, or priority for them in their caregiving role.</td>
</tr>
</tbody>
</table>
Table 4.1

**Caregiver Demographics**

<table>
<thead>
<tr>
<th>Age (Years; range 22-87)</th>
<th>Total (N=355)</th>
<th>Rural (n=124)</th>
<th>Urban Large (n=119)</th>
<th>Urban Small/Medium (n=112)</th>
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<td>30-39</td>
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<td>2</td>
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<td>40-49</td>
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<td>15</td>
<td>13</td>
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<tr>
<td>50-59</td>
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<td>45</td>
<td>34</td>
<td>21</td>
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<td>60-69</td>
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<td>48</td>
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<tr>
<td>70-79</td>
<td>58</td>
<td>21</td>
<td>15</td>
<td>22</td>
</tr>
<tr>
<td>80-89</td>
<td>13</td>
<td>3</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Not reported</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Mean Age (Years)</strong></td>
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<td><strong>61.07</strong></td>
<td><strong>60.34</strong></td>
<td><strong>61.31</strong></td>
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<table>
<thead>
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<th>Years of Caregiving Experience</th>
<th>Total (N=355)</th>
<th>Rural (n=124)</th>
<th>Urban Large (n=119)</th>
<th>Urban Small/Medium (n=112)</th>
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<td>10-20</td>
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<td>21+</td>
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<tr>
<td>Not reported</td>
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<td>1</td>
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<th>Relationship to Care Recipient</th>
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<th>Urban Large (n=119)</th>
<th>Urban Small/Medium (n=112)</th>
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<tbody>
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<td>Caring for a spouse</td>
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<td>Caring for a parent</td>
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<td>93</td>
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<tr>
<td>Caring for a sibling</td>
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<tr>
<td>Caring for a friend or neighbour</td>
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<tr>
<td>Caring for a relative (e.g., aunt/uncle)</td>
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<table>
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Table 4.2

Care Recipient Demographics

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<th>Age (Years; range 55-104)</th>
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<th>Urban Small / Medium (n=122)</th>
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<tr>
<td>60-69</td>
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<tr>
<td>70-79</td>
<td>82</td>
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<td>30</td>
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<td>29</td>
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<td>100+</td>
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<td>1</td>
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<tr>
<td>Deceased</td>
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<td>12</td>
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<tr>
<td>Not reported</td>
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<td>5</td>
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<td><strong>82.44</strong></td>
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**Condition Type**  
*Note: Column totals are greater than N=396 due to multimorbidity.*

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<thead>
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<th>Total (N=396)</th>
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<th>Urban Large (n=134)</th>
<th>Urban Small / Medium (n=122)</th>
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<tbody>
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<td>Dementia/Alzheimer’s or related syndromes</td>
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<td>56</td>
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<tr>
<td>Neurological disorder</td>
<td>39</td>
<td>11</td>
<td>17</td>
<td>11</td>
</tr>
<tr>
<td>Heart, kidney, or lung condition</td>
<td>128</td>
<td>48</td>
<td>40</td>
<td>40</td>
</tr>
<tr>
<td>Cancer (any type)</td>
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<td>24</td>
<td>26</td>
</tr>
<tr>
<td>Frailty</td>
<td>74</td>
<td>31</td>
<td>27</td>
<td>16</td>
</tr>
<tr>
<td>Vision deficits</td>
<td>20</td>
<td>7</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Mental health related disorders</td>
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<td>3</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Diabetes (type not disclosed)</td>
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<td>6</td>
<td>8</td>
<td>4</td>
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<tr>
<td>Arthritis</td>
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<td>Poor nutritional intake</td>
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<td>1</td>
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<tr>
<td>Post-stroke</td>
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<td>7</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Blood condition</td>
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<td>2</td>
<td>0</td>
<td>0</td>
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<tr>
<td>More support needed due to ageing</td>
<td>9</td>
<td>2</td>
<td>4</td>
<td>3</td>
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<tr>
<td>Acquired injury</td>
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<td>1</td>
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<tr>
<td>Prefer not to disclose</td>
<td>11</td>
<td>3</td>
<td>3</td>
<td>5</td>
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</tbody>
</table>
Table 4.3

Response Word Counts to Main Survey Questions

<table>
<thead>
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<th>Question</th>
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<th>Total Word Count</th>
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<tr>
<td>2) What do you find is positive about your caregiving role?</td>
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<td>5</td>
<td>5600</td>
<td>16</td>
<td>195</td>
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<td>3) What do you think is most important for support in your caregiving role?</td>
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<td>3</td>
<td>9099</td>
<td>26</td>
<td>295</td>
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*Rounded to nearest whole number

**Minimum response word count = 1
Figures

Figure 2.1

PRISMA 2020 Flow Diagram for Identification of Studies via Databases, Registers, and Other Sources

Nurse researchers at the University of Saskatchewan are looking to gather the perspectives of Saskatchewan informal and family caregivers to determine what caregivers to older adults need for support in their role. All persons with any current or previous level of involvement in caregiving to older adults in their lives are welcome to participate! Please fill out our survey at the link below if you are interested in participating.

**https://www.surveymonkey.ca/LINK**

The survey will be available until July 20, 2022. Stay well and take care! *This study has been approved by the University of Saskatchewan’s Behavioural Research Ethics Board (ID # 3377).*

Les infirmiers chercheurs de l'Université de la Saskatchewan cherchent à recueillir les points de vue des personnes aidantes de la Saskatchewan afin de déterminer quelles sont leurs besoins auprès des personnes âgées pour le soutien dans leur rôle. Toutes les personnes, quel que soit leur niveau d'implication dans la prestation de soins aux personnes âgées, sont invitées à participer à notre sondage. Pour le remplir, cliquez sur le lien ci-dessous.

**https://fr.surveymonkey.ca/LINK**

L'enquête sera disponible jusqu'au 20 du juillet 2022. Portez-vous bien et prenez soin de vous ! *Cette étude a été approuvée par le comité d'éthique de la recherche comportementale de l'Université de la Saskatchewan (ID # 3377).*
The Caregiver Experience: A provincial survey to gather perspectives and set priorities for caregiver support in Saskatchewan, Canada

Participant Consent Form

Thank you for your interest in participating in this research study. Before beginning the survey, please review the details of this consent form before proceeding. Important information about the study and informed consent is detailed below. Please note that you do not need to identify yourself on this consent form or at any point during this survey.

Researchers
This study is being conducted by Steven Hall, a registered nurse, and Master of Nursing student at the University of Saskatchewan. The study is supervised by Dr. Noelle Rohatinsky, an Associate Professor within the College of Nursing. Their contact information is listed below.

- **Student Researcher:**
  Steven Hall BSc BSN RN, Master of Nursing Student
  Phone: 306-966-5362 | Email: steven.hall@usask.ca

- **Supervisor:**
  Dr. Noelle Rohatinsky RN MN PhD, Associate Professor
  Phone: 306-966-4096 | Email: noelle.rohatinsky@usask.ca

Purpose and Objective of the Research
The purpose of this study is to gather and describe the experiences and perspectives of caregivers in Saskatchewan, and to identify the priority support needs of the caregivers in Saskatchewan. The objectives are to explore the caregiver experience in urban and rural settings within the province and identify the priority support needs to better assist caregivers in their role.

Procedures
This study involves your participation in this short online survey. Demographic information will be collected first and then you will have the opportunity to respond to four questions in open text boxes. The estimated time commitment for this survey is approximately TBD minutes.

Potential Risks
The questions in this survey will be asking you about the positive aspects and potential challenges you experience as a caregiver to an older adult in Saskatchewan. Reflection on these topics may be distressing to you. Please only answer those questions you are comfortable with. Suggested supportive contacts are available below if you have outstanding questions or needs for support. Below are contacts for supportive counselling should you become distressed or wish to discuss any emotions that may be elicited from participating this survey.

- **Saskatoon Caregiver Information Support Centre:** 306-652-4411
Potential Benefits
The goal of this research study is to understand the caregiver experience in Saskatchewan and provide direction for the implementation of support programming. The findings will be of ongoing benefit to caregivers in Saskatchewan, but specific benefits or outcomes are not guaranteed.

Confidentiality
Participation in this survey is anonymous. The data from this research project will be used in the student researcher’s thesis, as well as published and presented at conferences; however, your identity will be kept anonymous. Although direct quotations may be reported from your responses, no demographic information other than urban or rural setting will be attached to the quotation and any identifying information will be removed from the report. The first three digits of your postal code will be requested in the first part of the survey. This is only collected to determine distribution of participants across the province and will not be published or presented in any way. A geographic map of general area pinpoints will be generated but pinpoints on the map will be large enough to not identify specific areas.

Storage of Data
This survey is hosted by SurveyMonkey. Your data will be stored in facilities hosted in Canada. Please see the following for more information on the SurveyMonkey Privacy Policy. Survey response data will be exported from the SurveyMonkey interface on July 20, 2022, when the survey closes to participants. The exported data will be stored a password-protected computer during analysis and will be moved to the University of Saskatchewan OneDrive server for long-term storage once analysis is complete. Data will be stored on the USask OneDrive for five years post-completion of this study, at which time it will be erased beyond recovery.

Right to Withdraw
Participation in this survey is voluntary. You can decide not to participate at any time by closing your browser or choose not to answer any questions you do not feel comfortable with. Survey responses will remain anonymous. Since the survey is anonymous, once it is submitted it cannot be removed.

Follow-Up
To obtain results from the study, you may access a summary of results on the Saskatchewan Caregiver Experience Study public Facebook page when it becomes available. Alternatively, you may email any of the researchers for a general summary. Results will be available by April 2023.

Questions or Concerns
If you have questions or concerns, please contact the researcher(s) using the information at the top of this consent form. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board.
Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office: ethics.office@usask.ca; 306-966-2975; out of town participants may call toll free 1-888-966-2975.

*By continuing to complete this survey, your free and informed consent is implied and indicates that you understand the above conditions of participation in this study.*

[Continue to Survey]
Figure 4.1

Geographic Settings

[Diagram showing the distribution of geographic settings: Rural 35%, Urban (large) 33%, Urban (small/medium) 32%]
Figure 4.2

Map of Participants from Postal Codes
Figure 4.3

Types of Caregiver Training

*Orientation to Role was a term first mentioned in this thesis work in Chapter 2.*

**Continuing Care Assistants (CCAs) are also sometimes referred to in Saskatchewan as a Special Care Aides (SCAs). In other settings in Canada, (e.g., Ontario) CCAs are referred to as Personal Support Workers (PSWs). The most commonly used term for the same role in the United States is Certified Nursing Assistant (CNA).
Figure 4.4

Content Analysis Mind Map

- **Challenges**
  - "Am I doing it right?"
  - Navigating complex systems
  - "Living my own life"
  - Caregiving is exhausting
  - Caregiving at a distance

- **Support Priorities**
  - Optimizing the care recipient's health
  - An ear to listen and a shoulder to lean on
  - "Help when we need it"

- **Positive Aspects**
  - Having the ability and opportunity to care
  - Ensuring quality care for the care recipient
  - Personal growth through being a caregiver
  - Caregiving is rewarding
  - Caregiving is NOT a positive experience
  - Healthcare professionals that care
  - Improved policies, legislations, and regulations

- **The Saskatchewan Caregiver Experience Study**
## Appendix A

MEDLINE (OVID Interface) Search Strategy (Conducted July 2, 2021)

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## Appendix B

Targeted Community Facebook Groups by Population Centre

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<td><strong>Humboldt</strong></td>
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