Caregiving and Grieving During the COVID-19 Pandemic:
A Retrospective Study of Lived Experience, Palliative Care and Bereaved Caregivers

By

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Abstract

Caregivers play integral roles in providing care and support to individuals who are facing end of life. It’s imperative that health care professionals working in palliative care understand their lived experiences in order to provide appropriate support and address their needs. The COVID-19 pandemic has impacted people globally and changed the ways in which people provide and receive care. This phenomenological study explored the lived experiences of bereaved caregivers who provided care to a loved who was at the end of their life during the COVID-19 pandemic. Two in-depth semi-structured interviews were conducted with five bereaved caregivers. Thematic analysis was completed to analyze the data and five key themes were identified. 1) Impact of caregiving and the implications of public health orders, 2) interrupted grief and commemoration during a pandemic, 3) challenges with the health care system, 4) people make the difference, and 5) recommendations through reflections. Sub-themes within each key theme were identified. A detailed review of the findings, a discussion and recommendations are presented after a thorough review of the literature and discussion of the methodology and methods which informed this phenomenological study.

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Dedication

To the five bereaved caregivers who participated in this study,
this thesis is dedicated to you and all those who were caregivers for a loved one facing end of life during the COVID-19 global pandemic.

Thank you

♥

“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need a caregiver.”

– Eleanor Rosalynn Carter

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Chapter 1: Introduction

Caregiving for a loved one who is at the end of their lives can be both a rewarding and challenging experience. Although there may be some shared experiences amongst caregivers, the caregiving experience remains unique and personal. As the population continues to age and people continue to develop chronic, serious, and terminal illnesses, the role of caregivers and the importance of understanding their experiences has growing importance (Arnup, 2018; Williams et al., 2015). Furthermore, as the number of people living with life-limiting illness continue to grow, the demand on palliative care "which focuses on relieving suffering and improving the quality of life of patients and their loved ones during life-limiting illness" will increase (Canadian Institute for Health Information, 2023).

Family caregivers who provide care or support to someone who is at end of life (EOL) face practical and psychosocial implications related to EOL caregiving (Arnup, 2018). These EOL caregivers play integral roles in providing care and support to their loved ones and play a critical role in the provision of palliative care.

On March 11th 2020, the World Health Organization declared COVID-19 (COVID) as a global pandemic (World Health Organization, 2020a). As a result of the pandemic, there were additional challenges related to EOL and these challenges impacted palliative care clinicians as well as EOL caregivers (Kent, et al., 2020). Recent literature on the pandemic and the effects it has had on caregivers reveals that caregivers experienced higher levels of stress than they typically experience as a result of challenges brought on by COVID (Dang et al., 2020). Researchers highlight specifically, for palliative care caregivers the pandemic "had a radical impact on some family caregivers, causing emotional despair" (Wind et al., 2022, p. 6).

Statement of the Problem

A review of the recent literature revealed that the area of caregiving for someone with an advanced or terminal illness has been extensively researched (Adejumo et al., 2019; Bialon & Coke, 2012; Breen et al., 2018; Chandran et al., 2016; Dionne-Odom et al., 2021; El-Jawahri et al., 2021; Gardiner et al., 2022; Grande et al., 2021; Hovland et al., 2021; Kim et al., 2017; Kramer et al., 2011; Michaels et al., 2022; Nielsen et al., 2016a, 2016b, 2017a, 2017b; Rogalla, 2020; Spatuzzi et al., 2022; Stajduhar, 2013; Tang et al., 2021; Ullrich et al., 2017, Wen et al., 2021; Wen et al., 2022a). The research on family caregiving during the COVID global pandemic is only beginning to emerge (Becqué et al., 2022; Burke et al., 2021; Gergerich et al., 2020; Hanna et al., 2021; Holland et al., 2020; Kim et al., 2021; Nyblom, 2022; Wind et al., 2022). As a result of the limited existing research on COVID, and the ever-evolving nature of the pandemic as a whole, gaps remain in the body of research related to the experience of caregivers at EOL during the pandemic. Additionally, the lived experiences of these caregivers at EOL during COVID is a newer area of research in Canada and in the province of Manitoba.

Challenges in the family caregiving experience pre-date the COVID pandemic and have existed for decades. North America has an aging population. The health care system is not equipped to meet the needs of the aging population. The health care system has depended on caregiver support in providing individuals with the assistance required to manage their health while living with an advanced illness (Kent, et al., 2020). The literature reflects that caregiving at EOL impacts the physical, financial and psychosocial health of EOL caregivers. The challenges caregivers have been facing for decades were further amplified by the pandemic and it’s imperative that these lived experiences are explored in order to address caregiver needs and provide appropriate and adequate support.

As a result of COVID, the ways in which people interacted, received support and accessed health care and health related supports were all interrupted (Dang et al., 2020). Little is known about the caregiving experience during COVID or the bereavement journey of these caregivers. Their experiences with the interdisciplinary palliative care team during the pandemic is another important area to explore. Family caregivers and health care professionals work alongside one another in providing care and support to individuals facing end of life. It is essential that this area of caregiving during COVID is researched in order for social workers and other health care professionals working in EOL care to develop a better understanding of this caregiving experience. By understanding their experiences, health care professionals can be better equipped to provide person-centered care which addresses their needs. The COVID pandemic created unprecedented times and this study was an opportunity to share the rich narratives of family caregivers' lived experiences as well as collect insight into their bereavement experience.

Purpose of the Study

The main purpose of this research study was to explore the lived experiences of bereaved caregivers who provided EOL care during the COVID pandemic. Bereaved caregivers are a subset of caregivers who have experienced the death of someone they provided care to. This retrospective study aimed to explore this topic with bereaved caregivers in the context of the first year of COVID in the province of Manitoba.

Goal of the Study

The specific goal of this study was to develop a deeper understanding of family caregiver experiences. Highlighting caregiver voices and seeking to understand bereaved caregivers' lived experiences was the primary goal of this study. This study emerged from a passion for social work and palliative care and a desire to create an opportunity for social workers and other health care professionals working in palliative care to learn from the true experts of the palliative care patients and clients they all care for: the family caregivers.

Overview: Setting the Foundation

In general, caregivers are the people who provide informal care and support to an individual and this care can be physical, emotional or practical. Health care professionals and health care workers are formal caregivers. Informal caregivers refer to individuals who are providing care whom are unpaid and are family members or friends of the care receiver (Williams et al., 2015). In this qualitative study, bereaved caregivers are defined as the people who provided care and support to individuals who died. This study further defines a bereaved caregiver as anyone who identifies as one regardless of family relation or the type of care or support they provided. The terms family caregivers, caregivers, EOL caregivers and bereaved caregivers will be used interchangeably throughout this document to refer to all informal caregivers who provided care and/or support to someone who was at the end of their life. The term loved one will be used to refer to the deceased individual as all five of the participants in this study expressed love for the person they provided care to. This term will be used to honour this loving relationship expressed by study participants between the caregivers and care receivers.

Palliative care is defined by the World Health Organization (2020b) as an approach to care which focuses on the relief of suffering in the physical, psychological, social and spiritual domains. The World Health Organization (2020b, para 3) also states “palliative care is explicitly recognized under the human right to health”. A palliative approach focuses on quality of life. Palliative care be provided at any stage of ones’ illness. This study focuses on EOL palliative care and the terms EOL, palliative and advanced illness will be used throughout the document.

A palliative approach to care at end of life offers holistic support to individuals who are dying and support to their families. In Canada, in order to qualify for federal EOL benefits, a terminal illness is defined as “a disease state that cannot be cured or adequately treated and is reasonably expected to result in death within six months” (Government of Canada, 2023a, para. 3). Similarly, the Winnipeg Regional Health Authority Palliative Care Program includes as part of the criteria for enrollment in the program a prognosis of 6 months or less (Winnipeg Regional Health Authority, 2021). This study focuses on bereaved caregivers who provided care to a loved one who was enrolled on the Winnipeg Regional Health Authority Palliative Care Program at the time of their death.

There are a variety of advanced illnesses amongst those who receive palliative care. Although there is a significant amount of literature on the experiences of caregivers who provide care/support to individuals living with dementia, a large amount of the existing literature on palliative care and specifically EOL caregiving focuses on advanced cancer with some focus on advanced neurological diseases and end-stage organ diseases. Cancer is a disease where the trajectory can be more predictable which allows for the opportunity to discuss palliative care (Canadian Institute for Health Information, 2023).

The Canadian Institute for Health Information (2018, p. 7) reports that “although there is unmet need for palliative care across all disease groups, cancer patients were 3 times more likely to receive palliative care than others, both in hospital and at home”. They also explain in their 2023 report on Access to Palliative Care in Canada that individuals with cancer were most likely to be identified as palliative at 77% while only 39% of individuals with dementia received palliative care in the last year of their life (Canadian Institute for Health Information, 2023, p.

15). The literature review for this study heavily focused on palliative and EOL care in relation to advanced cancer and some focus on advanced neurological diseases and end stage organ diseases. Research exploring the lived experiences of caregivers of individuals living with dementia and their experiences with COVID remains an important area of research but is not the focus of this particular study.

Health care professionals who support individuals and families at EOL encompass a variety of disciplines who are employed into different roles on the interdisciplinary health care team. Social workers are an integral part of the interdisciplinary palliative care team. Bosma and colleagues (2010) explain that the values which are inherent to the social work profession including the importance of looking at individuals holistically, aligns with the focus of palliative care to alleviate both physical and emotional suffering while promoting dignity and quality of life.

This study is important as it is an opportunity for health care professionals to understand the lived of experiences of bereaved caregivers during COVID. This study is important as it aims to explore practice and policy implications with an overall purpose to understand what health care professionals can learn from family caregivers.

It is important to note that this research study was not about individuals who died from COVID and their caregivers. Rather, this study focused on the bereaved caregivers who cared for individuals at EOL who died during COVID from a pre-existing advanced disease and were receiving a palliative approach to care.

The lived experiences of family caregivers at EOL have implications for health care professionals. As it has been mentioned, the overall aim of this study was to highlight the voices of family caregivers by exploring their lived experience and as a result, the goal of this study was to expand the existing knowledge of caregiving at EOL while contributing to a new area of research related to the COVID pandemic.

Chapter 2: Literature Review

Research Strategy

To obtain literature related to family caregivers at EOL, the impact of caregiving at EOL, the bereavement experience of family caregivers at EOL, social work and caregivers at EOL and caregiving at EOL during COVID, the University of Manitoba library was searched. The focus was on peer reviewed journals locally, nationally, and internationally. Literature from the past 15 years was included in the search with a special focus on literature dated within the last 10 years. Keywords and their synonyms were searched on their own and in conjunction with one another to find relevant literature. Key terms included: caregiving, family, end of life care, palliative care, impact of caregiving, financial impact, physical impact, psychosocial impact, bereavement, grief, anticipatory grief, complicated grief, COVID, pandemic, caregiver experience and caregiver burden.

In addition to using the University of Manitoba library search engine, a number of different databases were manually searched using these terms including Taylor & Francis Online, SAGE Journals, Free Medical Journals, ProQuest, PsychINFO, EBSCOhost, PubMed, ClinicalKey, Health and Medicine, Palliative Care via Oxford Scholarship Online and ScienceDirect. All of these databases were accessed using the University of Manitoba library. The Journal of Social Work in End of Life and Palliative Care was also searched manually using the key words. A number of key areas were identified in the search of existing literature. The literature review will discuss the key areas that emerged based on this comprehensive search.

Palliative and End of Life Care

Palliative care is a holistic approach to care which aims to enhance quality of life and reduce suffering by managing pain and symptoms (Health Canada, 2018). This is a holistic approach which addresses the psychological, social, emotional, spiritual and practical domains of EOL (Health Canada, 2018).

Altilio & Otis-Green (2011) explain the contributions of social work to palliative care and highlight three key skills for social workers “1) expertise in navigation of medical and social systems, 2) its knowledge base in the support, education and interventions with patients, families and interdisciplinary teams, and 3) its commitment to social justice and alleviation of health disparities” (Altilio & Otis-Green, 2011, p. 22). This is consistent with the eleven social work competencies for practice in palliative care which includes advocacy, assessment, care delivery, care planning, community capacity building, confirmation, decision making, education and research, information sharing, the interdisciplinary team, and self-reflective practice (Bosma et al., 2008). The Canadian Association of Social Workers (CASW) does not specifically comment on core competencies for palliative care social workers but these core competencies align with the CASW scope of practice statement on social work practice. The CASW highlights the role of social work in their practice statement which includes but is not limited to, a holistic view of the person in their environment and improving health and social well-being (Canadian Association of Social Workers, 2020). The Canadian Hospice Palliative Care Association (2023) recognize these eleven competencies developed by Bosma and colleagues (2008) for palliative care social work and they recognize social workers as core members of the palliative care team.

Palliative Care, Dying and Caregiving in Canada

In Canada, it is estimated that 90% of deaths each year are a result of chronic illness which includes a variety of cancers, progressive neurological diseases, organ failure, dementia or frailty (Health Canada, 2018, p. 4). As it has been mentioned, the Canadian Institute for Health Information (2018, p. 31) estimates that individuals with cancer were 3 times more likely to receive palliative care and although individuals across different disease groups also require a palliative approach, this demonstrates the prevalence and need for palliative care amongst those living with cancer.

Individuals who receive palliative care die in a variety of settings including at home, in hospices and in long term care facilities (Canadian Institute for Health Information, 2018). Based on a review of the literature, it is clear that regardless of the location of death, caregivers play essential roles in the provision of end-of-life care. Of those who received palliative care at home, 99% of these individuals received care from family and friends (Canadian Institute for Health Information, 2018, p. 37).

It is documented that 6 million people in Canada provide unpaid care while also participating in the workforce (Canadian Hospice Palliative Care Association, 2020, p. 7). This illustrates the key role caregivers play in the provision of care and the multiple roles and responsibilities caregivers hold. In Canada, 44% of caregivers for palliative clients are adult children while 43% are spouses (Canadian Institute for Health Information, 2018, p. 37). Sixty-four percent of palliative clients lived with their caregiver (Canadian Institute for Health Information, 2018, p. 37). One third of family caregivers report that they experienced a level of distress including feelings of anger and depression (Canadian Institute for Health Information, 2018, p. 38). This distress and the impact of caregiving at EOL will be explored further in this literature review.

Social Determinants of Health and Palliative Care

The social determinants of health are described by the World Health Organization (2023) as the non-medical factors that influence health outcomes. The social determinants of health are important to consider in the discussion about caregivers at EOL as not all caregivers have access to the same resources or supports. Gardiner and colleagues (2020) suggest that the financial costs associated with caregiving at EOL is an issue of equity. They go on to explain that the social determinants of health impact EOL experiences and access to palliative care (Gardiner et al., 2020). Culture, gender, geography, the life course stage and economic differences all impact the EOL caregiving experience (Giesbrecht et al., 2012). These factors can also impact access to supports and as a result of these inequities, some family caregivers at EOL are particularly vulnerable (Giesbrecht et al., 2012). Some caregivers at EOL will experience a higher level of caregiver burden than others as a result of the inequitable access to resources, supports, housing, and other social factors which impact health. COVID has created additional challenges and it's important to explore the caregiver experience at EOL in the context of the pandemic.

Impact of Caregiving at End of Life and Caregiver Burden

Caregiver burden and the overall impact of caregiving at EOL has been documented in the recent literature (Anderson & White, 2018; Bialon, & Coke, 2012; Olson, 2014; Stajduhar, 2013; Williams et al., 2015). Caregiver burden is reported to increase throughout the caregiver journey (Guerriere et al., 2016). There are over a million family caregivers in Canada who are proving EOL care (Williams et al., 2015). This illustrates the high number of individuals who are actively involved in the care of a loved one who is at EOL. The impact of caregiving is a term that is also referred to as caregiver burden in the literature (Bialon, & Coke, 2012; Stajduhar, 2013; Williams et al., 2015).

Caregiving at EOL is described as all-consuming as it impacts all areas of the caregiver's life (Breen, et al., 2018). Caregivers play multiple roles and juggle multiple responsibilities which can result in an overall feeling of burden which negatively impacts the caregiver's well-being (Bialon & Coke, 2012; Williams et al., 2015).

Key areas related to the impact of caregiving and caregiver burden were identified in the review of the literature. This following section of the review will discuss these key areas including the financial impact, physical impact, the psychosocial impact, and what is referred to in the literature as the positive impacts of caregiving.

Financial Impact of Caregiving at End of Life

There are significant financial implications associated with caregiving at EOL. Several studies discuss caregiving at EOL and the negative financial impact on the caregiver (Chi et al., 2018; Gardiner et al., 2014; Gustavson & Dal Santo, 2008; Williams et al., 2015). Gardiner and colleagues (2020) suggest that the financial cost related to caregiving at EOL should be seen as a social determinant of health specific to end-of-life care. Home care services in Canada include access to limited nursing care, equipment and medication coverage but, caregivers still carry the financial responsibilities related to caring for somebody who is at EOL (Stajduhar, 2013). For example, in Manitoba, home care does not provide 24-hour care. A Canadian study which compared non-EOL caregivers to EOL caregivers revealed that EOL caregivers (n=471) had a higher use of government financial supports compared to other caregivers (William et al., 2015). This demonstrates how EOL caregivers are impacted financially and resort to government financial support. The researchers suggested that “end of life care may be more demanding on financial resources than non-end of life care” (Williams et al., 2015, p. 222).

Not all caregivers at EOL experience the same level of financial distress. Caregivers with lower socioeconomic status experience higher levels of caregiver burden (Ahn et al., 2012; Gardiner et al., 2014; Nielsen et al., 2016a). Caregiving at EOL can also impact employment. Stajduhar (2013) found that some caregivers have to temporarily stop work or reduce the number of hours worked. This is consistent with a recent international study (Gardiner et al., 2022) which explored employment and family caregiving in palliative care. They found that caregivers had to make changes related to their working practices which included changes related to the number of hours worked, working patterns and temporarily or permanently giving up employment (Gardiner et al., 2022). There are higher levels of burden experienced in certain caregiver cohorts such as employed adult caregivers and unemployed spousal caregivers (Bialon & Coke, 2012). Caregivers who are still in the workforce may be forced to take time away from work in order to act as caregivers. Depending on employment status and the benefits available, this time away from work may be paid or unpaid. There are public and private benefits available in Canada for caregivers at EOL. Some caregivers have access to and can use sick benefits for caregiving purposes but not all do (Wasner et al., 2013). If sick benefits are available, they may run out and then caregivers are only left with the option of applying for government assistance programs (Wasner et al., 2013).

The Compassionate Care Benefit (CCB) through Employment Insurance provides Canadians with paid time away from work to care for a terminally ill loved one but, this benefit only provides a portion of the individual’s income and is a short-term income support program (Williams et al., 2015). The goal of the CCB is to alleviate financial stress for caregivers at EOL. Unfortunately, the CCB is time limited with an eligibility criterion, requires documentation from a physician and the amount received is only 55% of your income up to a maximum cut off of $595 a week (Government of Canada, 2021b). Additionally, part time, seasonal or casual workers or those who are unemployed may not meet the criteria of insured hours required to be eligible for CCB (Giesbrecht et al., 2012).

The financial situation of caregivers at EOL varies greatly as workplace policies related to EOL caregiving vary. In a Canadian study which explored workplace policies, Vuksan and

Williams (2012) found that larger workplaces were more likely to have formal policies for leaves while smaller workplaces had informal policies but were more likely to offer flexibility to their employees.

Overall, caregivers at EOL experience financial burdens. In Canada, the CCB is available for some caregivers but not everyone is eligible and not everyone can afford to take a cut to their income. The social determinants of health and specifically, socioeconomic status, impact the level of financial stress and burden experienced by caregivers.

Physical Impact of Caregiving at End of Life

Caregivers at EOL can experience lower general health scores than the general population (Grande et al., 2018). In their 2018 study, Grande and colleagues (p. 1608) found that caregivers who were in the 25-44 age group and those in the 75+ age group had lower general health than the general population. Wasner and colleagues (2013, p. 81) found that 56% of their participants (n=27) reported that they believed their health issues were a result of their caregiving role. Although this statistic is relevant to this review, this study focused solely on caregivers of primary malignant brain tumour patients (Wasner et al., 2013). Although generalizations cannot be made, it is documented in the literature that the physical health and general well-being of caregivers at EOL is impacted by their caregiving role, regardless of the disease of the care receiver.

Women in particular are disproportionately reported as experiencing a negative impact on their physical health as a result of their caregiver role (Anh et al., 2012; Spatuzzi et al., 2022). In a 2021 study, (n=102), researchers found that older female caregivers experienced poorer physical health and higher levels of burden compared to men (Spatuzzi et al., 2022). Poor physical health is associated with fewer social supports while better physical health is associated with higher income and access to resources (Anh et al., 2012). This demonstrates how different factors which impact caregivers such as physical well-being, social supports, income and access to resources can all be interrelated.

In their phenomenological study which focused on the lived experience of caregivers, participants shared that caregiving had impacts on their physical health including worsening chronic conditions and increased fatigue (Bialon & Coke, 2012). Of the nine participants in Bialon & Coke's 2012 study, seven participants reported that their health deteriorated and some participants shared that existing health conditions worsened by lack of sleep or stress. Physical needs increase as the condition of the person facing EOL worsens and this can have physical as well as emotional implications (Bialon & Coke, 2012). One adult child caregiver who provided care for her dying mom stated "when she started falling out of bed, I could not pick her up — physically, could not pick her up. And I'll never forget that feeling. That was the most desolate, helpless feeling" (Bialon & Coke, 2012, p. 215). The lived experience of this caregiver illustrates not only the physical demands of caregiving but this also demonstrates that the physical impact of caregiving at EOL is interrelated with the emotional impact and the feeling of helplessness when the caregiver is physically unable to care for the terminally ill individual.

The literature is consistent in suggesting that the emotional and physical health of the caregiver is negatively impacted by EOL caregiving (Grande et al., 2021; Guerriere et al., 2016). Although, in some studies caregivers share that there are positive emotional impacts of caregiving (Anderson & White, 2018) no study in this literature review suggested that there are positive physical impacts of caregiving at EOL.

The Sandwich Generation. In general, caregivers at EOL experience poor health outcomes and the literature reflects that the sandwich generation is particularly at risk. The sandwich generation is described by Giesbrecht and colleagues (2012) as the family caregivers who are adult children to the care receiver whom are also caregiving for their own young children. This sandwich generation worry about their dependents both older and younger and as a result, some of these caregivers may neglect their physical as well as emotional needs (Anderson & White, 2018). In Anderson and White's 2018 study, one adult child caregiver in the sandwich generation stated:

> I get frustrated because I want to be there for him, and yet I have a daughter at home, who is only 11. So, I'm torn between needing to be there for her, needing to be there for my husband, needing to be here for my dad, needing to help my sister, and my other siblings. Sometimes I feel like there is this little piece of me being put in all these different compartments of my life and I sometimes wish there was a little more support, in some way, for the person stuck in my situation. The sandwich generation as they are calling it. (p. 270)

This direct quote from this qualitative study highlights the burdens experienced by the middle generation who are caring for more than one generation of family members and the impact on their overall health and well-being from their caregiving responsibilities (Anderson & White, 2018). This study confirmed the burdens experienced by the sandwich generation. These findings are supported in Nielsen and colleagues (2016a) study who reported that adult children who had young children and worked full time reported the highest level of caregiver burden.

Overall, the literature suggests that there are significant physical impacts related to caregiving at EOL and as life expectancy continues to rise and more people live with serious illness, the needs of the sandwich generation as well as other caregivers will be important to continue to explore as well as the long-term effects on their physical, financial and emotional health.

Psychosocial Impact of Caregiving at End of Life

The psychosocial impact of caregiving at EOL will be discussed in this section of the literature review which includes a discussion on anxiety and depression as well as the positive impacts of caregiving at EOL.

The psychosocial impact of caregiving at EOL is captured in several studies that explore caregiver experience at EOL using a variety of theories and methodologies such as phenomenology (Bialon et al., 2012), ecological systems theory with phenomenological design (Chandran et al., 2016), ethnography (Hebert et al., 2009), narrative (Lobb et al., 2019) and constructivist grounded theory (Clark et al., 2011).

A theme across several studies is the importance of communication and education at EOL (Chandran et al., 2016; El-Jawahri et al., 2021; Lobb et al., 2019). Caregivers in a study which focused on the experience of bereaved caregivers (n=28) who navigated a home-based death revealed that caregivers found it distressing to witness their loved one deteriorate and caregivers wanted preparatory information to help prepare them for the EOL changes (Lobb et al., 2019). Similarly, communication issues (Chandran et al., 2016) and feelings of ill preparedness at EOL, feelings of helplessness, and the importance of being provided education at EOL were all reported by caregivers (El-Jawahri et al., 2021). Based on the review of this literature, it appears that health care professionals working in EOL care play an important role in alleviating and addressing emotional distress and the psychosocial impact of caregiving at EOL by providing preparatory information and educating caregivers on the dying process and what they can expect as death nears.

Anxiety and Depression. Caregiver burden can manifest as feelings of anxiety, depression, and emotional distress (Guerriere et al., 2016). It is experienced by caregivers throughout the illness trajectory and can continue into bereavement (Guerriere et al., 2016). Ullrich and colleagues (2017, p. 6) found in their study on quality of life, psychological burden, needs, and satisfaction of family caregivers of advanced cancer patients (n=54) that 43% of participants reported moderate to severe anxiety. Forty-one percent reported moderate to severe depression and overall, the researchers found that family caregivers experience decreased psychosocial well-being (Ullrich et al., 2017, p. 6). Participants in Ullrich and colleagues (2017) study were caregivers whose loved one was a patient on a palliative care unit at the time of data collection. Similarly, Wasner and colleagues (2013, p. 81) reported in their study on the psychosocial care for caregivers of primary malignant brain tumour patients, 45% of caregivers reported increased anxiety and 33% reported increased depression (n=27). Although these statistics are relatively consistent, data for both studies were collected while the caregivers were actively providing care rather than data collected retrospectively. Consistent with these findings, in a 2021 study of 168 bereaved caregivers of advanced cancer patients of mixed malignancies, 30.4% reported significant depression and 43.4% reported anxiety (El-Jawahri et al., 2021, p. 490). With the sample sizes of 54, (Ullrich et al., 2017), 27 (Wasner et al., 2013) and 168 (El-Jawahri et al., 2021), respectively, this illustrates that depression and anxiety are experienced by caregivers at EOL regardless of the primary cancer diagnosis. It is important to note that these findings are all from studies where the diagnosis of the terminal individual was an advanced cancer.

Compared to the wide range of studies which focus specifically on the psychosocial impact of caregiving at EOL for individuals with advanced cancer, only a handful of studies on end-stage organ disease or end-stage motoneuron diseases were found. Adejumo and colleagues

(2019) explored the psychological impact of caregiving at EOL for individuals with end-stage chronic kidney disease. They found that caregivers (n=57) had significantly higher rates of anxiety and depression (31.6% vs 5.3% and 31.6% vs 3.5%) compared to a control group (Adejumo et al., 2019, p. 192). Overall, caregivers of end-stage chronic kidney disease patients have “increased burden and impaired psychosocial well-being compared to controls” (Adejumo et al., 2019, p. 193). Pagnini and colleagues (2010) found that in caregivers of individuals with amyotrophic lateral sclerosis (ALS) depression, anxiety and caregiver burden were predicted by social support and increased social support reduced psychological distress. Feelings of anxiety and depression were also related to the patients functioning and overall status (Pagnini et al., 2010).

Based on this review of the literature, anxiety and psychosocial distress are present in the EOL caregiver population. The literature also demonstrates that there is a psychosocial impact to caregiving at EOL regardless of the diagnosis. Although this review does not encompass all of the literature, the findings are consistent across the studies discussed above. These findings are important for all health care professionals and most notably, social workers, as their role in palliative care is to provide skilled psychosocial support. It has been discussed that palliative care is a holistic approach to care. It’s imperative that the psycho-emotional needs of caregivers at EOL are addressed and supported by social workers.

Positive Impact of Caregiving at End of Life

This section of the literature review has thus far focused on the challenges related to the financial, physical and psychosocial impacts of caregiving at EOL. Some of the literature reflects the positive impacts of caregiving at EOL such as feelings of gratitude and feeling close to your loved one (Anderson & White, 2018). Although only a small number of the studies reviewed mention the positive aspects of caregiving, this could be a result of the focus of the study and the type of questions that were asked. In the review of the literature, the studies where positive impacts of caregiving were included in the findings are all studies that were qualitative, exploratory with open ended questions with a focus on inquiring about the positive aspects of caregiving.

Jo and colleagues (2007) found in their Canadian study with spousal caregivers and care recipients (n=10 dyads) that although negative aspects of caregiving were reported, participants also reported that their caregiving experience "strengthened their relationship with their spouse due to the increased time spent together and shared decision making they experience" as well as "discovering emotional strength and physical abilities" (Jo et al., 2007, p. 16). This is consistent with other findings. It is reported in the literature by Anderson & White (2018) that caregivers viewed their caregiver role as a privilege (n=73) and by Hovland & Mallet (2021) as an opportunity to create a deepened connection and closeness with their loved one (n=30). It is also viewed as an opportunity to reciprocate love to a parent in adult child caregivers (Anderson & White, 2018). In all three studies, the researchers specifically asked participants about their positive experiences associated with their caregiving role. As a result, the findings of these studies reflect both the negative aspects and challenges as well as the positive aspects and rewards of caregiving at EOL.

Preparedness and Expectations of Caregivers at End of Life

The literature discusses the importance of caregiver preparedness for EOL, caregiver expectations at EOL and the implications this has on overall well-being and bereavement experiences. Several studies address preparedness (Breen et al., 2018; Hebert et al., 2009; Tang et al., 2021; Wen et al., 2021; Wen et al., 2022a) and caregiver expectations at EOL (Burns et al., 2015; Matthews & Daigle, 2020; Wennman-Larsen & Tishelman, 2002).

Preparedness for Death

Preparedness for death encompasses the medical knowledge caregivers possess of their loved ones' dying process, the practical matters associated with EOL, and the emotional and behavioral dimensions of preparing for the death of a loved one (Breen et al., 2018). Preparedness for death impacts the overall psychosocial well-being of caregivers. Researchers found that death preparedness of family caregivers of newly diagnosed advanced cancer patients was associated with caregiver mental health related quality of life and it was revealed that caregivers who are not prepared for the death of their family member report depressive symptoms and worse quality of life compared to caregivers who were more prepared (Wen et al., 2022a).

There is an important relationship between preparedness for death and the after-death grief experience. A study on the associations of death preparedness and bereavement outcomes for caregivers at EOL found that higher death preparedness resulted in a lower likelihood of severe depressive symptoms (Wen et al., 2021). Similarly, Tang and colleagues (2021) found in their longitudinal study that emotional preparedness of caregivers is associated with lower levels of depressive symptoms and improved quality of life. Researchers found that in instances where caregivers did not have adequate emotional preparedness, negative EOL experiences including severe symptoms of depression were reported (Tang et al., 2021).

Hebert et al., (2009) found that caregivers reported different dimensions that were important to them in their preparations for death. This included being provided with practical information and being given support in finding closure and acceptance (Hebert et al., 2009). This finding is consistent with the findings of studies that were discussed earlier in this literature review related to the psychosocial impact of EOL caregiving and the importance of communication and education to alleviate distress (Chandran et al., 2016; El-Jawahri et al., 2021; Lobb et al., 2019). The literature reviewed in this section revealed that preparedness at EOL is closely associated with the psychosocial well-being of caregivers and emotional preparedness impacts the caregivers' ability to cope with the overall impacts of caregiving including the physical, financial, and psychosocial impacts.

In a phenomenological study on caregiver experience, caregivers shared that hospice staff as well as the caregivers themselves were focused on the present and the immediate needs of the palliative patient and as a result, there was little preparatory education or support (Tabler et al., 2015). Preparedness for death is also reflected in Breen and colleagues (2018) qualitative study which focused specifically on caregiver preparations for death and explored to what extent caregivers felt they were prepared, what helped them prepare, and what may help them feel more prepared. In the discussion of this study, the researchers make the distinction between being prepared and being forewarned (Breen et al., 2018). In other words, simply the knowledge of the terminal diagnosis is not enough for caregivers to feel prepared. It goes beyond being informed of a prognosis. Rather, in order to be prepared for death, caregivers must feel prepared on different levels including cognitively, behaviourally, and emotionally (Breen et al., 2018; Hebert et al., 2009).

The findings of these studies demonstrate the importance of emotional preparedness for caregivers. Caregivers are at a risk of complicated, prolonged grief, and psychological distress without adequate and multidimensional preparedness for the death of their loved one. Social workers play an integral role is supporting caregivers in building their coping strategies and emotionally preparing for the death of a loved one. This requires skilled psychosocial counselling skills.

Expectations at End of Life

Caregiver expectations at EOL encompass expectations of the EOL experience, expectations of the palliative care team, but also expectations on the role of the caregiver. Caregiver expectations at EOL is associated with caregiver satisfaction (Wennman-Larsen & Tishelman, 2002). Understanding caregiver expectations at EOL has important implications for the interdisciplinary health care team as they play a role in reducing death anxiety of caregivers (Matthews & Daigle, 2020). Caregivers at EOL may have their own set of expectations of what their caregiving experience will be.

Burns and colleagues (2015) looked at the gap between caregivers expectations of their EOL caregiving experience and their actual experience. In their survey of 1628 caregivers they found that 48.3% of caregivers reported a worse caregiving experience than what they expected (Burns et al., 2015, p. 455). These researchers suggested that in order to improve caregiver satisfaction with their EOL experience, it’s imperative that caregiver expectations are understood (Burns et al., 2015).

The expectations of caregivers in an inpatient hospice setting were explored in a 2020 study by Matthew and Daigle. The researchers used a service quality instrument called the SERVQUAL to analyze caregiver perception of service quality at EOL in hospice. They asked caregivers about their expectations of hospice services as well as their perception of the quality of the service received (Matthew & Daigle, 2020). They present a practical approach and framework using the SERVQUAL analysis for the interdisciplinary palliative care team to use in practice based on the responses from caregivers regarding their expectations of quality service at EOL and what they would consider a good experience in a hospice setting. In their study, they found that the different domains of the SERVQUAL analysis including reliability, assurance, empathy, and responsiveness were interconnected (Matthew & Daigle, 2020). For example, participants explained that they wanted to feel prepared for the death and be provided information which related to the domain of responsiveness and they wanted this communication to demonstrate caring which related to the domain of empathy (Matthew & Daigle, 2020)., Matthew & Daigle (2020) found that when caregivers felt they received quality service, they experienced improved quality of life, their expectations of service were met, and they experienced positive caregiver satisfaction.

Caregiving and Grief

In this section, this writer will discuss various components related to grief. This section will begin with defining both anticipatory grief and complicated grief. After, both of these topics will be discussed in further detail and a review of the literature as it relates to anticipatory grief and complicated grief will be integrated. This section will include a brief review of prolonged grief disorder.

Grief is the response to a loss. Auger (2007, p. 205) explains that grief is the reaction as well as the experience people have in response to a loss while bereavement is “the process of learning to cope with sustained losses throughout our lives”.

Anticipatory grief is the mourning process that begins before a person dies when caregivers are expecting the death of their loved one. In the literature it is referred to as the grieving and preparation before the death in anticipation of the loss (Toyama & Honda, 2016). The term anticipatory grief is used interchangeably in the literature with the term pre-loss grief (Nielsen et al., 2017b). Coelho and colleagues (2020, p. 700) refer to anticipatory grief as the loss that is experienced during EOL caregiving and state that “anticipatory grief is defined as the family response to the perceived threat to the other's life and the subsequent anticipation of loss in the context of the end-of-life caregiving relationship". It is important to note that a key aspect of anticipatory grief is that the death is expected and not a sudden death.

Complicated grief is described as an after-death experience of "intense, persistent grief for more than six months after the loss, which impairs psychological, social and daily functioning" (Nielsen at al., 2017a, p. 541). Complicated grief has been found to be associated with the development of psychopathological disorders and increased mortality (Guldin et al., 2012). The American Psychiatric Association (2022) added prolonged grief disorder to the DSM-5-TR as a result of studies which demonstrated the persistent difficulties in bereavement people experienced.

Anticipatory Grief

The literature regarding anticipatory grief is not consistent. There are researchers who suggest that there may be benefits to anticipatory grief (Olson, 2014; Tabler et al., 2015; Toyama & Honda, 2016; Rogalla, 2020). These include the opportunity to develop coping skills by preparing for the death, beginning to think about their day-to-day life without their loved one, and engaging in conversations related to anticipatory grief which may improve bereavement outcomes (Tabler et al., 2015). In one study (Olson, 2014), a caregiver at EOL shared their positive experience with anticipatory grief:

> I went through a lot of anticipatory grief because I knew he was going to die and he wasn't the same person anymore. So that made it a lot easier for me when he did die because I had already been through all this, I had separated emotionally. (p. 556)

Other researchers suggest that the experience of anticipatory grief can be "beneficial for individuals when dealt with correctly" (Toyama & Honda, 2016, p. 2). Similarly, Rogalla (2020) suggests that if individuals use proactive coping techniques during their anticipatory grief they may experience personal growth.

Nielsen and colleagues (2016b; 2017a; 2017b) have contributed to the literature on anticipatory grief and complicated grief with several published and peer reviewed studies. Contrary to the researchers who suggest there are positive aspects of anticipatory grief, Nielsen and colleagues (2016b; 2017a; 2017b) explain that anticipatory grief does not necessarily alleviate or improve the bereavement experience after death and anticipatory grief can have significant negative effects on caregiver's well-being. This is consistent with Johansson and Grimby (2012, p. 134) who acknowledge that the experience of anticipatory grief can create the opportunity for someone to begin to prepare themselves for the impending death but they state that "the mental impact of both pre and post loss may have detrimental effects on the health of the bereaved" (Johansson & Grimby, 2012). This review of the literature demonstrates the inconsistencies in the literature relevant to anticipatory grief and also reflects how each caregiver's grief experience can vary.

There are several studies in the literature which discuss the experience of anticipatory grief which includes feelings of emotional stress, loneliness, sadness, cognitive dysfunction, withdrawal, and avoidance (Johansson & Grimby, 2012). It is reported that anticipatory grief is associated with a high degree of caregiver burden, low feelings of preparedness for death, and depressive symptoms (Nielsen et al., 2017b). In their qualitative study, Coelho and colleagues (2020) explored family caregivers and their experience with anticipatory grief and found what they refer to as two main dimensions of anticipatory grief which includes traumatic distress and separation distress. The former was found to be linked to a feeling of a lack of control over the illness and the threat the illness had on their loved ones' life whereas separation distress was linked to the distress over the future separation between the family caregiver and their loved one (Coelho et al., 2020).

Preparing caregivers for EOL is key to improving the caregiver experience of anticipatory grief. In a systematic review of the literature on caregivers at EOL and bereavement, Nielsen and colleagues (2016b) found that high preparedness for EOL was associated with improved caregiver outcomes. The researchers suggest that caregivers with low preparedness and those experiencing pre-loss grief should be provided support (Nielsen et al., 2016b). A narrative approach is suggested by Toyama and Honda (2016) and in their qualitative study which had a social constructivist perspective, they found that using a narrative approach with caregivers at EOL was helpful in addressing their anticipatory grief.

Based on this review of the literature related to the experience of anticipatory grief, it is clear that anticipatory grief is associated with several distressing symptoms experienced by caregivers. It is imperative for social workers and other psychosocial clinicians working in EOL care to understand the experience of anticipatory grief and be able to identify the symptoms of pre loss grief in caregivers in order to offer support and interventions to both prevent and address anticipatory grief.

Complicated Grief

Complicated grief is “a disorder characterized by grief symptoms whose duration and intensity causes significant distress and impairment” (Ghesquiere et al., 2011, p. 217). There are particular risk factors for complicated grief related to the caregiving experience. The literature refers to complicated grief as prolonged grief (Ghesquiere et al., 2011; Lai et al., 2014; Mason & Tofthagen, 2019; Nielsen et al., 2017a). Complicated grief impacts ones’ ability to engage in their normal life and it requires intervention (Mason & Tofthagen, 2019).

As it has been discussed, several different factors impact the caregiving experience at EOL. This literature review has discussed the financial, physical as well as the psychosocial impact of caregiving along with preparedness for death and expectations. The Center for Prolonged Grief (2023) estimates that there are tens of millions of people in the world who are experiencing prolonged grief and 10-15% of the bereaved are struggling. In a study of 87 bereaved caregivers, questionnaires related to complicated grief and depression were completed and the researchers found that 15% of caregivers had moderate to severe depression and 40% experienced complicated grief (Guldin et al., 2012, p. 1682). These statistics demonstrate the prevalence of complicated grief amongst survivors of the deceased.

Predictors and Risk Factors. The recent literature on complicated grief reveals that family caregivers are at high risk of complicated grief as a result of their change in role after their loved one dies. Mason and Tofthagen (2019, p. 256) explain that caregivers "may feel guilt, abandonment, and loneliness after the death and may experience loss of purpose of identity when they are no longer a caregiver". The primary distinction between normal grief and complicated grief is often a lack of acceptance that the person has died (Bruinsma et al., 2015).

A review of the literature relevant to complicated grief revealed there are certain predictors and risk factors for complicated grief such as severe anticipatory grief symptoms, depressive symptoms, (Nielsen et al., 2017a) and caregiver burden (Lai et al., 2014). This illustrates how different domains of the caregiver experience are interrelated. The research reflects the importance of screening caregivers who may be at high risk for complicated grief (Ghesquiere et al., 2011).

Compared to men, women are at high risk to experience prolonged grief (The Center for Prolonged Grief, 2023). Across several studies, spousal caregivers were referred to as a cohort of caregivers who are at high risk for complicated grief (Bruinsma et al., 2015; Nielsen et al., 2017a). Socioeconomic factors such lower education level was also found to be a risk factor across several studies (Kramer et al., 2011; Mason et al., 2020; Neielsen et al., 2017a). In one study, researchers found that the strongest predictor of complicated grief was depressive symptoms associated with anticipatory grief (Nielsen et al., 2017a). This illustrates the importance for palliative care clinicians to address anticipatory grief before it develops into complicated grief post death. If these risk factors can be identified, social workers working with EOL caregivers can support caregivers pre death and work with caregivers to alleviate distress associated with complicated grief post death.

Protective Factors. Further in regards to complicated grief, there is relevant literature which mentions protective factors for caregivers (Kim et al., 2017; Kramer et al., 2011). In one study which looked at complicated grief symptoms in caregivers of individuals with lung cancer, researchers found that the involvement in a palliative care or hospice program served as a protective factor for complicated grief as it helped buffer patient’s fear of death which had a protective impact on the caregiver (Kramer et al., 2011). Caregivers who felt they were prepared for EOL, who were satisfied with the palliative care approach, and the caregivers who reported higher levels of spirituality were all found to have lower levels of prolonged grief (Kim et al., 2017). These findings have important implications for social workers who support caregivers during their caregiving experience as well as during bereavement. Researchers suggest that caregivers who are at risk of complicated grief need to be proactively identified by clinicians (Guldin et al., 2012). Further research into targeted bereavement services or guidelines for bereavement services in palliative care is needed to see if this may improve complicated grief outcomes (Guldin et al., 2012). Preparedness is an ongoing theme observed in the literature.

Support programs related to psychosocial support as well as education pre-death may help reduce the risk of complicated grief amongst caregivers post-death (Mason et al., 2020).

Prolonged Grief Disorder. In the DSM-5-TR, prolonged grief disorder is described as persistent and intense grief which causes significant distress and lasts for a period of time of over 12 months (American Psychiatric Association, 2022). Symptoms include emotional pain, a reduction in emotional experiences, feelings of meaninglessness, and difficulties with engaging amongst other symptoms (American Psychiatric Association, 2022).

In a 2019 study, Zordan and colleagues looked at the long-term prevalence of prolonged grief disorder in bereaved cancer caregivers. Researchers found that nearly 20% of caregivers (n=301) experienced symptoms of prolonged grief disorder for at least 3 years after the death of the person they provided care to. This highlights the long-standing effects of prolonged grief disorder and the researchers suggest that their findings demonstrate how imperative it is to proactively identify caregivers who may be at risk of developing prolonged grief disorder and this should occur while the patient is still alive (Zordan et al., 2019).

Wen and colleagues (2022b) explored the commonalities and differences in depression and prolonged grief disorder. Overall, they found that although there were commonalities in factors which predict depression and prolonged grief disorder, they remain distinct and “interventions should be tailored to bereaved family members’ unique risk profile” (Wen et al., 2022b). This supports the importance for social workers to provide person-centered care.

Summary of Anticipatory Grief and Complicated Grief in the Literature

Although grief is a normal and healthy response to death there are different types of grief and some that are more problematic than others. Anticipatory grief is the grief experienced before a loss while complicated grief is prolonged grief after a loss which can develop into prolonged grief disorder. Although there are inconsistencies in the literature relevant to anticipatory grief, there are consistent findings which highlight the importance for health care professionals working with caregivers at EOL to assess for anticipatory grief. The literature reflects the importance of psychosocial interventions and support to caregivers who experience anticipatory grief (Coelho et al., 2019; Johansson & Grimby, 2012; Tabler et al., 2015; Toyama & Honda, 2016) and this has important implications for social workers working in palliative care.

Caregivers at End of Life and Assisted Dying

In the review of the literature relevant to caregivers at EOL, Medical Assistance in Dying (MAID) and the caregiver experience as it relates to MAID is a key area of research that emerged. MAID is relatively new to Canada as it has only been legalized since 2016 (Government of Canada, 2023c). In a review of the literature specifically related to caregivers and MAID in general, three Canadian studies were identified (Hales et al., 2019; Holmes et al., 2018; Smolej et al., 2022) while other studies from the United States of America (Buchbinder et al., 2018) and Switzerland (Gamondi et al., 2013, 2018) were also identified. Although there are other studies related to MAID, these were the studies identified in this search which explored specifically the family caregiver experience with MAID.

Overview of Assisted Dying in Canada

In June 2016, the Supreme Court of Canada passed federal legislation, Bill C-14, which legalized MAID and since this legalization, the number of individuals accessing MAID continues to grow (Government of Canada, 2023c; Collier, 2016; Rahimi, 2017). Bill C-14 provides the framework for MAID and outlines who can receive MAID, how they can receive MAID and when they can receive MAID. Only certain individuals can provide MAID and in

Manitoba, the MAID team provides this service.

The interdisciplinary care team in Manitoba includes physicians, nurses, social workers, speech language pathologists and dieticians (Collier, 2016). Social workers play an important role on the team in providing psychosocial support to MAID clients and their families. The literature reveals that many requests for MAID have a psychosocial dimension (Antifaeff, 2019). Social workers have a specialized skill set. In her case study research, Antifaeff (2019, p. 190) explored how a social worker supported a patient and her family through MAID and this "improved everyone's ability to articulate their needs, speak the unspeakable, and celebrate her life in the way that was meaningful to her". Social workers play important roles across health care, including within the MAID team.

The law has a set criterion of eligibility that must be met in order for someone to be eligible for MAID. Individuals request MAID for a variety of reasons related to losses such as autonomy, independence, purpose, abilities, as well as suffering (Nuhn et al., 2018) and the literature reveals that overall, family caregivers are supportive of their loved ones decision to have an assisted death (Buchbinder et al., 2018; Holmes et al., 2018). In one study, a caregiver shared that MAID allowed the caregiver and the dying individual to have closure while another caregiver stated "if it had not been for MAID, my wife would have ended her life alone by her own hand and possibly earlier in her disease… knowing this was her option allowed time to reflect on a life that was well lived knowing the end would be a peaceful event" (Smolej et al., 2022, p. 4).

Caregiver Role in Assisted Dying

The literature demonstrates the important and integral roles of caregivers during the journey of MAID which has emotional as well as practical implications. In one qualitative study, Holmes and colleagues (2018) explored the experiences of caregivers who were supporting a loved one through an assisted death. Caregivers reported that they were offering emotional support to their loved one while simultaneously helping their loved one prepare for and arrange for their assisted death and caregivers reported that this felt strange (Holmes et al., 2018). Smoleg and colleagues (2022) found that family caregivers reported they were the ones to first initiate the conversation about MAID with their healthcare provider and participants in this study expressed wanting more transparency from medical providers on MAID as an option.

A focus across two studies involved caregivers and the phases of their involvement throughout the MAID process. In one study, contemplation, gaining acceptance, gaining permission, organization, and after were themes related to caregiver involvement (Gamondi et al., 2018). Similarly, preparation, ingestion (the physical act of ingesting the medication), waiting, and after death were found in Buchbinder and colleagues (2018) study. Caregivers reported they provided emotional and instrumental support during these phases of involvement (Buchbinder et al., 2018). Based on this review, it is observed that caregivers play significant roles throughout the MAID process.

A sense of relief, opportunities for closure, and a focus on spending time together were all reported as part of family caregivers' experiences with MAID in Smoleg and colleagues' 2022 study. The literature also demonstrates that caregivers' experience with MAID can potentially have negative impacts on their well-being and how they cope with the loss. Caregivers have reported that they neglected their own feelings of anticipatory grief during the MAID process in order to focus on their loved one (Buchbinder et al., 2018). It has been discussed in this literature review that in situations of a natural death, caregivers can experience anticipatory grief. This review found no studies which explored specifically the experience of anticipatory grief in caregivers in the context of an assisted death. Based on this review, it appears that this may be a gap in the literature. Caregivers whose loved one had an assisted death may have unique needs. As a result of the growing number of individuals accessing MAID, it is important for social workers and other health care professionals to understand whether or not the prevalence or the experience of anticipatory grief or complicated grief of caregivers differs in situations of a natural death versus an assisted death.

Improvements

Although caregivers have been found to be supportive of their loved one’s decision to have MAID (Buchbinder et al., 2018; Holmes et al., 2018), caregivers also suggest improvements to the MAID process (Hales et al., 2019; Smoleg et al., 2022). Caregivers have identified key areas for improvement such as operational improvements, further clarity on the MAID process, suggested improvements related to bereavement, and ensuring support is offered leading up to the MAID provision (Hales et al., 2019). Other suggestions include more support with the administrative aspects of MAID (Smoleg et al., 2022). Identifying the specific needs of caregivers who are supporting a loved one through MAID is critical and further research on this area is needed.

Caregiving and the Pandemic

COVID in Canada

This literature review has discussed the literature relevant to a number of key areas pertinent to caregiving at EOL. A new area of research that is emerging is related to caregiving at EOL during the global COVID pandemic. On January 7th, 2020 the Government of Canada activated emergency response plans, restricted border entry and began testing efforts and on January 25th, 2020 the first confirmed case of COVID was reported in Canada (Public Health

Agency of Canada COVID-19 Surveillance and Epidemiology Team, 2020). COVID spread quickly throughout the country and by June 2nd, 2020 there were 92,151 cases reported across 12 provinces and territories (Public Health Agency of Canada COVID-19 Surveillance and Epidemiology Team, 2020). As case numbers continued to rise, provinces implemented public health measures across the country. In Canada, public health measures included physical distancing and limiting interactions to people within the same household (Detsky & Bogoch, 2020). The COVID pandemic impacted the provision of palliative care services. According to a 2021 report, “COVID-19 further strained already limited palliative care resources and exposed pre-existing gaps and systemic vulnerabilities in palliative care delivery across in-home and community-based settings across Canada” (Government of Canada, 2021, p. 3).

Caregiver Experience

Research on caregiving for someone with advanced illness during the pandemic is beginning to emerge (Becqué et al., 2022; Burke et al., 2021; Gergerich et al., 2020; Hanna et al., 2021; Holland et al., 2020; Kim et al., 2021; Nyblom, 2022; Wind et al., 2022). Whether the terminally ill individual was cared for at home, on an inpatient unit, a hospice setting, or in a long-term care facility, COVID impacted the caregiving experience. A detailed document from Health Canada and several partner organizations outlines the lessons learned related to community-based palliative care during COVID and it states “caregivers who cared for a loved one at home experienced a sharp increase in caregiving duties at a time where there were limited supports” and “the need for greater psychosocial, physical, and practical supports for caregivers has previously been identified as a priority and requires focused and sustained attention beyond the pandemic” (Healthcare Excellence Canada, et al., 2021).

As part of the public health orders, visiting in private dwellings were restricted (Detsky &

Bogoch, 2020) as well as in facilities (Hanna et al., 2021; Holland et al., 2020). This new and growing body of literature reflects the increased distress and caregiver burden experienced by family caregivers during COVID (Hanna et al., 2021; Holland et al., 2020; Sannes et al., 2020; Wind et al., 2022).

Isolation. It has been documented that pre pandemic, caregiving at EOL can be an experience of emotional strain and sadness (Johansson & Grimby, 2012; Lai et al., 2014). Feelings of loneliness and isolation have been further amplified by the COVID crisis (Kent et al., 2020). In a paper which discussed caregivers caring for individuals with cancer during COVID, Sannes and colleagues (2020) explain that caregivers are at a double hit risk for social isolation as a direct result of physical distancing and visitor restrictions. Caregivers who were caring for their loved one at home reported that they struggled on their own without their regular support system present and in some cases, to alleviate the isolation, some caregivers who did not live in the home with their loved one report that they broke the public health regulations as they worried the primary caregiver could not cope on their own (Hanna et al., 2021). Although feelings of isolation and loneliness were present in situations of home-based deaths during COVID, some caregivers whose loved one was in an inpatient setting feared that their loved one would die alone without family present (Holland et al., 2020). As a result, some caregivers opted to discharge their loved one from an inpatient setting and pursue a home-based death (Holland et al., 2020). The literature also reflects the fear experienced by caregivers related to COVID transmission from health care staff (Healthcare Excellence Canada, et al., 2021) and the powerlessness relatives felt when they their loved one was isolated (Becqué et al., 2022).

Caregiving whilst Home-Schooling. In March 2020, across Canada, public health orders enforced the closure of schools, universities and non-essential businesses (Detsky & Bogoch, 2020). The impact of this was detailed in an article about how the family caregiving crisis was met with a pandemic. Specifically, the authors explain that the sandwich generation of caregivers have competing responsibilities further challenged by COVID as a result of school closures and new home-schooling responsibilities on top of their caregiving responsibilities for their ill loved one (Kent et al., 2020). This finding demonstrates the multiple hats caregivers wear and also demonstrates how public health orders that were in place to help reduce infections in schools, directly impacted EOL caregivers. In this review of the literature, only one study (Kent et al., 2020) mentioned this middle generation of caregivers during COVID. Further research into their specific experience is needed.

Creative Visiting. The literature discusses caregivers and maintaining connection with technology and virtual supports (Burke et al., 2021; Sannes et al., 2020), window visits (Gergerich et al., 2020; Hanna et al., 2021) and communication using telehealth platforms (Gergerich et al., 2020; Sannes et al., 2020). In their qualitative study, Hanna and colleagues (2021) reported that while caregivers who were not physically with their loved ones were grateful for the opportunity of a window visit, this created its own distress as they could see each other but not touch and there were challenges associated with communicating through a window. Although virtual visiting and telehealth communication created opportunities for communication and connection, the literature also discusses the disparities involved with access to technology as well as the issue of digital literacy (Kent et al., 2020).

The importance of virtual connection extended into the bereavement phases of caregiving. As a result of COVID and gathering restrictions, funerals and memorial services were moved online instead of in person. Two studies discuss how health care professionals working in palliative care can support bereaved caregivers by encouraging them to plan virtual services and host virtual events to commemorate their loved one (Burke et al., 2021; Holland et al., 2020).

Another challenge related to creative and virtual visiting between individuals who were institutionalized during COVID and their caregivers relates to staffing and the availability of staff to facilitate these visits. Social workers are integral members of the palliative care team who have played a key role in facilitating communication but, in some facilities, social workers were deemed non-essential (Gergerich et al., 2020). If health care staff were deemed non-essential, they were restricted from entering into health care facilities (Gergerich et al., 2020). This created further obstacles and challenges associated with communication and connection at EOL as a result of visiting restrictions.

In facilities where social work was deemed essential, they were mobilized in some cases to play untraditional roles in hospitals and health facilities including facilitating creative visiting and communication with families. Although there were instances of this in Manitoba, no literature was found in this review specific to Manitoba. Burke and colleagues (2021) provide an example of an interdisciplinary team coming together during COVID to support patients and families in creative ways. A Family Support Team comprised of palliative care social workers, intensive care unit social workers, palliative care chaplains, and a clinical psychologist came together at the beginning of COVID at a large Midwestern medical centre in the United States (Burke et al., 2021). This team provided psychosocial support through the facilitation of virtual visits, having family members send them photos to share with patients, through a Zoom support group, and bereavement care over the phone amongst other interventions (Burke et al., 2021). The importance of family and community are values that are important to the profession of social work and social workers are experts at navigating systems and advocating for individuals, families, groups, and communities (Canadian Association of Social Work, 2020).

Grieving. COVID impacts life as well as death and the experience of grief and bereavement amongst survivors. Holland and colleagues (2020, p. 54) explain that “grieving during the pandemic has become disorganized”. Caregivers experienced complicated grief as a result of COVID and a lack of interaction with their support networks, feelings of guilt if they were unable to care for a loved one at home, and a disruption in time spent together if visitor restrictions were in place (Holland et al., 2020). This is consistent with Hanna and colleagues (2021) and Becqué and colleagues (2022) who found that bereaved caregivers were unable to physically be with their loved one before they died to say a final goodbye. This theme of separation and disruption in time together was also reported by social workers working in hospice care who stated “the stress and range of emotions is difficult enough when someone you love is dying, but with the added separation it is torture” (Gergerich et al., 2020). This literature review has discussed complicated grief and the predictors and risk factors for complicated grief such as severe anticipatory grief symptoms, depressive symptoms (Nielsen et al., 2017a), and caregiver burden (Lai et al., 2014). Further research is necessary to explore the prevalence and experience of complicated grief amongst caregivers at EOL who have been impacted by the COVID crisis.

COVID and MAID. This review has discussed how COVID impacted caregivers at EOL in several different ways. There is a new area of research emerging which explores how COVID impacted the experience of MAID. This review found one Canadian study in which interdisciplinary MAID team members were interviewed (Wiebe et al., 2021). A theme found in this study is the perception that suffering amongst individuals who were receiving MAID increased as a result of isolation and a reduction in services and one participant shared “when

I’ve done the assessment and I’m talking to the patients’ families, they talk about how horrible [it is] that they can’t visit, or if they’re at home, that they worry their loved one is going to have to go to hospital, and then they can’t visit or find out what’s going on.” (Wiebe et al., 2021, p. 402). This was the only study found in the review of the literature on MAID in a Canadian context as it relates to caregiving at EOL during COVID. This appears to be an area that should be researched further. In particular, research on bereaved caregivers who cared for someone during the pandemic who had an assisted death may be a gap in the literature.

Literature Review Summary

This review of the literature relevant to the topic of caregiving at EOL and the emerging research on COVID and caregiving at EOL set the foundation for this study. This review reveals that although the area of the caregiver experiences at EOL has been well researched, a new area related to COVID is beginning to emerge and what is known about caregiving at EOL during COVID must be further explored.

A synthesis of the literature revealed that the key areas identified in this literature review are interrelated. The financial impact of caregiving was found to be associated with poor psychological well-being which relates to the psychosocial impact of caregiving at EOL (Nielsen et al., 2016a). Poor psychological well-being had implications for poor health outcomes (Nielsen et al., 2016a; Wasner et al., 2013) which relates to the physical impact of caregiving. Importantly, high preparedness at EOL is associated with improved caregiver outcomes post death (Nielsen et al., 2016b). This illustrates the importance for social workers and other health care professionals to provide holistic care to caregivers at EOL. Holistic care addresses multidimensional needs including the physical, psychological, social, and spiritual domains. The review of the literature illustrates that the caregiver experience is multifaceted and the challenges experienced by caregivers may be further amplified by challenges created by COVID.

Social work is a profession which upholds self determination and understands that each person has their own unique life experiences, which can impact how someone deals with their role as a caregiver and the losses related to dying. The relationship between the caregiver and care receiver as well as their circumstances related to the social determinants of health, formal and informal support provided to the caregiver, and overall coping strategies could all have an impact on individual caregiver grief experiences. COVID created a new climate for caregiving and its imperative that the lived experiences of caregivers in the context of the pandemic is explored.

Overall, this literature review reveals important implications for social workers and other health care professionals as they are often on the front line with caregivers. In order for social workers to understand the needs of caregivers, social workers must be familiar with the financial, physical, and psychosocial impact of caregiving which can impact a caregiver's preparedness for death, their expectations, and their risk for both anticipatory grief as well as complicated grief. In addition and in relation to the above, caregiving at EOL and bereavement during COVID has its own unique challenges. This is a gap in the literature and this study aimed to contribute to this emerging area of research.

Chapter 3: Methodology and Methods

This chapter provides insight into the methodology as well as the methods used for this research study on the lived experiences of bereaved caregivers at EOL during the COVID pandemic. Qualitative research and research paradigms will be briefly discussed followed by a discussion of phenomenology which is the approach that guided this study. The methods section of this chapter will discuss in detail the research design, data collection methods, and data analysis.

Qualitative Research

There are two primary types of research: qualitative research and quantitative research. Quantitative research emphasizes the importance of scientific rigor, quantifiable data, and facts while qualitative research involves "purposeful investigations, searches or processes" with an aim to "collect and evaluate information in order to gain knowledge and understanding" (Carey, 2012, p. 4). Carey (2012) explains that there are two types of qualitative research: pure and applied. This study is a pure qualitative study as it aims to expand knowledge and gain awareness.

A qualitative approach was most appropriate for this social work research study which explores lived experience. Rather than test a hypothesis, this study aimed to gain knowledge from bereaved caregivers by collecting qualitative data through in-depth interviews which were analyzed using thematic analysis. Guba and Lincoln (1994) offer that qualitative and quantitative should be viewed in the context of methods and used to describe the types of methods used within a research study and their position is that both qualitative and quantitative methods may be used within any research paradigm. Specific methods used for data collection and data analysis will be discussed later in this chapter.

Research Paradigms

Research can be done based on a variety of worldviews, belief systems, and theoretical frameworks (Guba & Lincoln, 1994; Morris, 2006; Wahyuni, 2012). A researcher's position on the nature of reality, their view on what constitutes acceptable knowledge, the values that guide the research, and the model that the research is conducted within are all informed by the research paradigm (Wahyuni, 2012). In other words, the ontological, the epistemological, and the axiological beliefs, as well as the methodology the researcher uses are based on the research paradigm. Morris (2006) discusses four main research paradigms: positivism, post-positivism, critical theory, and constructivism and all can be used to guide social work research.

There are philosophical underpinnings and beliefs that differentiate each research paradigm: ontology, epistemology, and axiology. Methodologies also vary across the paradigms. Guba and Lincoln's 1994 writing on paradigms, Morris's 2006 textbook on research methods and Wahyuni's 2012 article have all set the foundation for this author's knowledge and understanding of paradigms as it relates to research.

Ontology, Epistemology and Axiology

Ontology is a branch of philosophy that studies how we perceive reality, which can be objective or subjective (Guba & Lincoln, 1994; Wahyuni, 2012). When discussing ontology a researcher is either a realist and views reality as objective or a researcher views reality as subjective and is a relativist. Epistemology is the branch of philosophy which studies knowledge and in which ways knowledge is acceptable (Wahyuni, 2012) and the relationship between the researcher and what is to be researched (Guba & Lincoln, 1994). A researcher either takes an etic approach to research and they are on the outside looking in or they take an emic approach and they are immersed within the research and the gathering of knowledge. Wahyuni (2012) also explains axiology, as the branch of philosophy concerned with values and ethics, and methodology, as the different models behind the research process.

The Constructivist Paradigm

Constructivist research is qualitative and constructivists can use a variety of different methodologies in their research. Morris (2006) explains that the constructivist paradigm is the only paradigm of the four paradigms that takes a subjective view of reality and the data that is gathered in a constructivist study is subjective data. In order to do constructivist research the researcher needs to be immersed in the study and engaging with the research participants. This is the emic approach to research and is related to epistemology. Ontologically, constructivists believe that reality is socially constructed and therefore, there are multiple realities and those realities should be explored. In terms of axiology, constructivists believe that research can be influenced by the researcher’s values as a result of the subjective, emic approach in this paradigm (Wahyuni, 2012).

Phenomenology

There are several different methodologies within the constructivist paradigm and phenomenology is one of these approaches. Phenomenological research aims to understand the unique point of view of research participants and explores how “people interpret and make sense of the world in which they live” (Carey, 2012, p. 85) and phenomenology aims to describe a common meaning (Creswell, 2018). This is why phenomenology was chosen for this research study as it aims to understand meaning in the context of human experience and the meanings that people attach to their realities (Lopez & Willis, 2004). Specifically, interpretive phenomenology was elected as the approach for this study. Creswell (2018) explains that phenomenology is commonly used in social sciences as well as health sciences.

Phenomenology is a methodology for research but it first was viewed as a philosophy in Germany prior to World War I and the term phenomenology has Greek roots and means “to flare up, to appear” (Dowling, 2007). As a philosophy, it offers a perspective on how to describe a phenomenon, how a person experiences phenomenon, and is the study of the life world and lived experience (Tuohy et al., 2013). There are two widely used and known types or schools of phenomenology. Husserl’s descriptive phenomenology and Heidegger’s interpretive phenomenology. New perspectives of both descriptive and interpretive phenomenology have developed over time. This study used Heidegger’s interpretive phenomenology. This study used the term interpretive phenomenology to describe the study methodology but it’s important to note that interpretive phenomenology is also referred to in the literature as hermeneutic phenomenology (Creswell, 2018; van Manen; 1990)

Descriptive versus Interpretive

The next section will briefly discuss Husserl’s descriptive phenomenology and Heidegger’s interpretive phenomenology as it was through further readings on each type of phenomenology that the researcher identified interpretive phenomenology as the type of phenomenology most appropriate for this study’s research methodology.

Husserl’s Descriptive Phenomenology

Edmund Husserl is referred to as the father of phenomenology (Tuohy et al., 2013). The literature explains that he is responsible for introducing the life world and lived experience (Dowling, 2007; Koch, 1994) and he believed that a scientific approach was needed to study human experience (Lopez & Willis, 2004). Koch (1994) explains that Husserl’s descriptive phenomenology can be categorized as intentionality, essences, and bracketing.

A key aspect of Husserl’s descriptive phenomenology is bracketing which is the belief that the research should “shed all prior personal knowledge to grasp the essential lived experiences of those being studied” (Lopez & Willis, 2004, p. 727). He emphasized that reality is objective, that a scientific lens could be used to study human experience, and preconceived ideas should be set aside (Dowling, 2007; Lopez & Willis, 2004; Tuohy et al., 2013).

Heidegger’s Interpretive Phenomenology

Husserl’s student, Heidegger, challenged some of Husserl’s views regarding phenomenology and primarily challenged bracketing (Koch, 1994). Heidegger’s interpretive phenomenology embraces “pre understanding” and the knowledge or understanding one has cannot be eliminated (Koch, 1994; Lopez & Willies, 2004). Instead, this knowledge is a valuable guide to inquiry (Lopez & Willis, 2004). A concept central to interpretive phenomenology is the hermeneutic circle which emphasizes understanding as a circular process which is continuous and all parts are looked at separately, across each other, and then as a whole (Tuohy et al., 2013).

Interpretive phenomenology takes phenomenology a step further than descriptive as it moves beyond describing phenomena and instead, seeks to interpret and describe human experience and the meanings people attach to their realities (Lopez & Willis, 2004). This is one of the primary reasons why interpretive phenomenology was chosen for this research study rather than descriptive. This student researcher has experience working as a social worker in palliative care and rather than shed existing knowledge on EOL caregiving and the experience of caregiving and grieving during COVID, this student researcher used this knowledge to support and guide the inquiry into lived experience.

Methods

As it has been discussed, this is a qualitative study with an interpretive phenomenological methodological approach. This approach allowed for the collection of detailed lived experiences of caregivers who provided care at the EOL to help gain an understanding of their caregiving as well as their bereavement experience during the COVID pandemic.

Sample

The first presumptive case of COVID was reported on March 12th, 2020 (Manitoba Government, 2020a) and on March 20th Manitoba entered a state of emergency (Manitoba Government 2020b). Therefore, caregivers who provided EOL care during the first year of the pandemic, between March 2020-March 2021, were invited to participate. Inclusion criteria included that they provided care during the first year of COVID in Manitoba and their loved one died during this period of time. Bereavement is an ongoing experience and journey and therefore, this student researcher did not ask caregivers to focus on their grief during a specific period of time. Rather, participants were asked about their bereavement experience overall during COVID.

Sampling Strategy. An aim of this study was to collect rich qualitative data and as a result, a purposeful sampling strategy was used as it emphasizes the importance of having a sample that can support the development of a deeper understanding of the phenomena being studied (Carey, 2012). A phenomenological study focuses on the trustworthiness of the data and a purposeful sampling strategy using criterion-based case selection helps to ensure that the data collected from participants is specific to the aims of the study. Individuals met criteria for this study if they:

1) were over the age of 18

2) could speak, read, and write in English

3) identified themselves as a bereaved caregiver

4) cared for a loved one who was enrolled on the Winnipeg Regional Health Authority Palliative Care Program at the time of their death

5) provided care and/or support to their loved one at some point during March 2020-March 2021
6) their loved one died during the period of March 2020-March 2021

Sample Recruitment. Participants were recruited from the Winnipeg Regional Health Authority Palliative Care Program through the interdisciplinary health care team. A research poster (see Appendix A), a request for assistance with study recruitment letter (see Appendix B) and a study information letter (see Appendix C) were shared with the Winnipeg Regional Health Authority Palliative Care Program social workers/psychosocial clinicians, palliative care coordinators, community palliative care nurses and palliative care physicians. The interdisciplinary team were asked to contact potential participants and share the research poster and study information letter with them. Potential participants were contacted by phone by a member of the Winnipeg Regional Health Authority Palliative Care Program team and informed of the study. They were provided the student researcher's email and phone number. Then, potential participants contacted the researcher directly. The researcher reviewed the inclusion and exclusion criteria with potential participants to ensure they met all study criteria and the researcher answered any questions. Once it was confirmed that participants met all study criteria and participants confirmed their interest, the researcher sent them either by mail or email the informed consent form (see Appendix D), the list of free counselling resources (see Appendix E), the study information letter and the research study questions (see Appendix F). An honorarium of 25 dollars was provided to all participants in recognition and in appreciation of their time.

Sample Size. As this was a qualitative study and phenomenology involves in depth comprehensive interviews which results in rich data to analyze, this study sought a sample size of five to seven participants. Participants were interviewed twice. The researcher was able to include five bereaved caregivers in this study.

Setting. Participants were provided the option to be interviewed over the telephone or via Zoom, a video conferencing platform, for both of the interviews. All participants chose to meet over Zoom. As a result of COVID and to protect the safety of the participants and the researcher, in person interviews were not offered.

Data Collection

Demographic Form

A demographic form (see Appendix G) was created to collect information which provided additional context related to the caregivers' relationship to their loved one, their age, their loved ones' terminal illness, the date their loved one died, the location of the death (home, acute care or hospice), level of education of the caregiver, employment status of the caregiver, ethnic background, the type of caregiving responsibilities they had (physical, emotional care/support and/or financial support), and caregivers were asked how many hours in a week they provided care. All participants completed the demographic form with the student researcher at the beginning of the first interview. The researcher verbally asked the participant the questions and the researcher immediately recorded their responses on the demographic form. This information was collected as the literature review revealed that the social determinants of health are important to consider in the discussion about caregivers at EOL (Gardiner et al., 2020; Giesbrecht et al., 2012).

Semi Structured Interviews

According to Patton (2015) there are three types of qualitative data: interviews, observations/fieldwork, and documents**.** In phenomenology, data is collected using interviews as the researcher aims to collect rich narratives from participants. The researcher is viewed as the "interview instrument" (Morris, 2006, p. 213) and in depth semi structured interviews with open ended questions are often used. van Manen (1990) explains that the interview allows for the gathering of rich narratives and this format for data collections allows for a conversation between the interviewer (researcher) and the participant.

Interviews for this study were conducted over Zoom. The interviews were all audio recorded and transcribed by the student researcher. Two interviews were conducted with each participant. In the first interview, the student researcher used open ended questions with prompts and the second interview allowed for member checking, further clarification, and the opportunity to explore themes that had been interpreted from the transcript of the first interview.

Although the interviews involve a conversation between the researcher and the participant, van Manen (1990) suggests that there should be some structure to the interview. Therefore, in addition to the demographic form, data was collected using semi structured interviews and the interviews were guided by the following questions and their subsequent prompts:

1) Tell me about your experience as a caregiver at EOL during the pandemic

   Can you share any specific moments or experiences?

2) Tell me about your bereavement experience during the pandemic. Did the pandemic impact your bereavement experience and if so, how?

   Can you share any specific moments or experiences?

   How did it feel to grieve during a pandemic?

3) Did the pandemic impact you as a caregiver financially, physically or emotionally, and if so, how?

   Can you provide any specific examples?

4) Tell me about your experience with the palliative care team

   For example, the palliative care nurses, physicians, social workers

5) Tell me about what supports you were provided by the palliative care team

   Can you provide any examples of the support you received or suggestions for support you would have found helpful?

6) Do you have any recommendations on how the palliative care team can better support caregivers at EOL during the pandemic

   Are there any specific suggestions you have for the team during the caregiving experience as well as during the grief experience?

7) Is there anything else would you like to share about your caregiving or bereavement experience

These questions guided the conversation with the participant and the open-ended nature of the questions allowed for further sharing. The questions were a guide and they were informed by the aims and goals of the study, the student researcher’s clinical experience in palliative care, as well as the literature on caregiving at EOL. This is a retrospective study and the focus was on asking caregivers to draw a timeline of their caregiving experience and focus on the first year of COVID as this was a time when public health orders were first in place. The questions were provided to all participants prior to the first interview to respect the emotional nature of the study questions, to provide transparency regarding what the researcher would be exploring with the participant, and to allow for the participants to be reflective in this retrospective study. The researcher explained at the beginning of the interview that participants could skip any questions or pause and come back to a question. All five participants in this study answered all of the research questions. The second interview was essential in confirming with the participant that the researcher understood the lived experience shared by the participant and the second interview allowed the researcher to clarify details and ask further questions regarding initial themes from the first interview.

Reflective Journaling

In an interpretive phenomenological approach, researchers are encouraged to keep a reflective journal and they can write down thoughts, observations, and interpretations throughout the research process (Laverty, 2003). Lincoln and Guba (1985, p. 109) explain that reflective journals are “introspective journals that display the investigator’s mind process, philosophical position, and bases of decisions about the inquiry”. van Manen (1990) suggests that the researcher should log close observations and insights after each interview with a participant.

In addition to logging observations and insights from the interviews, the student researcher used the reflective journal to write down thoughts and feelings. The researcher has experience working as a social worker in palliative care and it was important for this student researcher to engage in reflective practice. Self-reflective practice is integral to social work and it involves an awareness of one’s own beliefs, values, attitudes, and experiences. The researcher has prior knowledge, beliefs, assumptions, and experiences as a palliative care social worker. Using a reflective journal, the researcher logged this information throughout the research process. During data analysis, the journal was reviewed in detail to support the interpretation process in the creation of themes that were interpreted from the data.

Data Analysis

Thematic Analysis

To analyze the data of this study, thematic analysis was used as the analysis strategy. Thematic analysis is a qualitative analysis method which can be used across different methodologies through rigorous analysis of data (Braun & Clarke, 2006). The goal is to have findings that are trustworthy (Braun & Clarke, 2006; Nowell et al., 2017). Thematic analysis is gaining recognition as a valuable analysis method (Braun & Clarke, 2012). It allows the researcher to look for patterns of themes and "allows the researcher to see and make sense of collective or shared meanings and experiences" (Braun, & Clarke, p. 57, 2012).

Braun and Clarke (2006; 2012) offer a six-phase approach to thematic analysis which includes:

Phase 1: familiarizing yourself with the data
Phase 2: generating initial codes
Phase 3: searching for themes
Phase 4: reviewing potential themes
Phase 5: defining and naming themes
Phase 6: producing the report

Familiarizing Yourself with the Data. In phase one, the researcher transcribes the data and reads through the entire data set while making notes on initial thoughts (Braun & Clarke, 2006). The data was read through during the data collection process as interviews were underway and transcribed. The student researcher completed all of the transcription for this study and Braun & Clarke (2006) explain that transcribing allows for the researcher to be fully immersed and promotes understanding of the data. After all interviews were completed, the student researcher read through the entire data twice to be fully engaged in the data set.

Generating Initial Codes. In phase two, the researcher begins to code themes by looking at interesting features in the data (Braun & Clarke, 2006). The transcripts from the interviews were all coded and the codes were systematically identified in the qualitative data and used to create themes in the next phase which are referred to as patterns of meaning (Clarke & Braun, 2017). A list of codes was created based off of all of the latent codes identified within each transcript. Full and equal attention was given to all of the data. The researcher highlighted each code in a different colour to help identify different codes as they emerged. During this process, the research also looked for interesting quotes as they related to different codes. At the end of this step, all of the codes were listed in an excel sheet and the data extracts for each code were collated together.

Searching for Themes. In phase three, the codes are sorted into themes. At this stage, the researcher printed off the long list of codes and individually cut them up so all codes were on their own piece of paper. Each code also corresponded to its own set of data extracts. Seeing all of the codes laid out separately allowed the researcher to see all of the codes identified in the data and consider how the codes related to one another. The codes were organized and moved around until in initial thematic map was created. An important part of this phase is thinking about “the relationship between codes, between themes, and between different levels of themes” (Braun and Clarke, 2006, p. 89). A list of potential themes and sub themes was created at the end of this phase of analysis.

Reviewing Potential Themes. In phase four, the themes are reviewed and refined in a two-level process which involves a review of the coded data extracts and then the researcher looks at the overall thematic map and the themes as a whole (Braun & Clarke, 2006). Five overarching themes with sub themes were identified in the analysis. The themes were identified by first refining themes and ensuring that the data within a particular theme “cohere together meaningfully” (Braun & Clarke, 2006, p. 91). Then, the identified themes were considered as a whole with the entire data set to ensure the themes “accurately reflects the meanings evident in the data set as a whole" (Braun & Clarke, 2006, p. 9).

Defining and Naming Themes. Braun & Clarke (2006) explain that the fifth phase focuses on defining and refining the themes and identifying the story of each theme and what data the particular theme captures. They go on to explain that it's important themes are not too broad or complex (Braun & Clarke, 2006). The specific themes and sub themes will be discussed in the findings and discussion chapters of this report.

Producing the Report. In the final phase of analysis, the researcher writes up the final report of the data that has been analyzed (Braun & Clarke, 2006). In the report of the analysis in the analysis chapter of this document, the researcher demonstrates why each theme is a theme in the data by using examples and in this analysis, the researcher uses quotes for each theme to help tell the story of the data.

Appropriateness of Thematic Analysis for this Study

Thematic analysis was appropriate to use for this interpretive phenomenological study as the purpose was to move past summarizing data and instead, thematic analysis interprets lived experiences and a key feature is its flexibility related to the research question, sample, and research methods (Clarke & Braun, 2017). It is an approach that can be used across a range of studies, theoretical frameworks, research questions, and through rigorous analysis, it can produce trustworthy data (Braun & Clarke, 2006; Nowell et al., 2017). Additionally, thematic analysis provides an approach where the researcher can examine lived experience and look at similarities as well as differences (Nowell et al., 2017) and researchers can look for themes in the meanings that participants attach to their experiences. As it has been mentioned, a key feature of Braun & Clarke's thematic analysis is flexibility. A researcher can provide a "rich thematic description of your entire data set" or a researcher can "provide a more detailed and nuanced account of one particular theme, or group of themes, within the data" (Braun & Clarke, 2006, p. 83). In this study, the researcher analyzed the entire data set using an inductive approach to thematic analysis focusing on latent themes in which themes are developed in an interpretative process and examines "underlying ideas, assumptions, and conceptualizations" (Braun & Clarke, 2006, p. 84).

Trustworthiness in the Data

This study used Lincoln & Guba's (1985) criterion for trustworthiness in the data. The four standards for trustworthiness are: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985).

Credibility. Lincoln & Guba (1985, p. 314) explain that "the most crucial technique for establishing credibility" is through member checks. Through member checking which occurred in the second set of interviews with the participants and in the in-depth interviews, the student research aimed to increase the credibility of the study. The interviews were audio recorded, transcribed verbatim, and throughout the analysis, the researcher consistently went back to the raw transcripts to ensure codes and themes were reflective of the raw transcripts.

Dependability. This researcher also strived for dependability by keeping a clear and detailed recording of the overall research process and by having a clear plan set out for the study's methodology.

Confirmability. Confirmability relates to the interpretations and findings and the detailed record of the interview transcripts, the documents of the analysis process, and the researchers reflective log which all illustrate how the researcher made decisions. Confirmability was maintained throughout this study by making notes about emerging themes after each interview, notes regarding themes that were interpreted during the entire data analysis process, and by referencing the journal throughout data analysis.

Transferability. Transferability relates to generalizability. Lincoln & Guba (1985) explain that one cannot know how findings may be transferred in another context and therefore, it is imperative that researchers attain transferability through rich thick descriptions. The researcher attains this by including rich thick descriptions of the participants lived experiences in the findings chapter of this study.

Ethics

Approval was received from the University of Manitoba Research Ethics Board (HE2022-0110) on July 8th, 2022 (see Appendix H) and an amendment was approved on September 23rd, 2022 (see Appendix I). This study also received approval from Shared Health Approval Committee for Privacy, Impact, and Access in Research (SH2022:113) on September 15th, 2022 (see Appendix J).

Chapter 4: Findings

This chapter discusses the bereaved caregivers who participated in the study and the findings of the thematic data analysis. A discussion of the findings will follow in chapter five.

This study explored the lived experiences of bereaved caregivers. Five key themes emerged from the data: 1) impact of caregiving and the implications of public health orders, 2) interrupted grief and commemoration during a pandemic, 3) challenges with the health care system, 4) people make the difference, and 5) recommendations through reflections. A number of sub-themes were identified and this chapter will review the themes and subthemes in detail.

Participants

Five bereaved caregivers participated in this study and each participant was interviewed twice. A demographic form was completed with participants at the beginning of the first interview. All participants self-identified as female with two identifying as spouses and three as daughters of their deceased loved ones. The age of participants ranged from 36-81. Hospital and home were the two locations of death reported by participants. The diagnoses of participants loved ones included metastatic breast cancer, amyotrophic lateral sclerosis (ALS), metastatic liver cancer, metastatic bladder cancer, and stage 4 lung cancer. The level of education of participants ranged from grade 12 to a PhD and some participants were actively working while others were retired. When asked about their ethnic backgrounds, three participants described their ethnic background as Caucasian, one identified as Canadian, and another identified as Ukrainian. Two participants identified their caregiving responsibilities as physical, emotional, and financial, while three participants described their responsibilities as emotional and physical. The average self-reported hours within a week participants provided care ranged from 20 hours a week to 24-hour full time care. Participants loved ones died during the period of May 2020-

January 2021. All participants chose to have their interviews over Zoom. Participants are identified as P1, P2, P3, P4, and P5. Confidentiality was discussed with all participants. The researcher explained to the five participants that their information would be kept confidential, their name would not be disclosed in the study nor would any identifying information be revealed. All five participants signed the informed consent form. The first interviews were approximately one hour in length and the second interviews were approximately 30 minutes in length.

Themes

Table 1: *Themes and sub-themes of caregiving and grieving during the COVID pandemic*

THEMES	**SUB-THEMES**
1) Impact of caregiving and the implications of public health orders	• Isolation and loneliness • Time away from work and the costs of the pandemic • Visiting restrictions and forced separation • The risk of COVID transmission • Stretching the rules • Lack of physical contact
2) Interrupted grief and commemoration during a pandemic	• Delayed and difficult grief • Funerals and celebrations of life in COVID
3) Challenges with the health care system	• Rotating staff • Not enough services • Negative experiences • COVID used as an excuse • COVID making a difficult time harder
4) People make the difference	• Staff
5) Recommendations through reflections	• A case for change

Theme One: Impact of Caregiving and the Implications of Public Health Orders

The impact of caregiving and the implications of the public health orders was a primary theme identified in the analysis of the data. Although this is a large theme, the researcher identified that the impact of caregiving was interconnected to the theme of the implications of public health orders and therefore, these two themes could not be separated. All participants spoke of how public health orders had an impact on their caregiving or bereavement experience in some capacity. When speaking overall about her experience caregiving and grieving during the pandemic, one participant spoke of how her experience impacted her in the way that it changed her as a person. She spoke of how isolated and alone she felt in caregiving for her mom and making decisions regarding her mom's care. Had there not been a pandemic, she wouldn't have had to do it on her own.

> I think it definitely it changed me as a person. I knew when we got that diagnosis for my mom because it was right before like literally ten days before the pandemic really hit that it would.. my life would be changed forever. But just knowing and thinking about the decisions that I had to make, I wouldn't wish that upon anybody and I just felt like I keep saying it was just so isolating because I had to make decisions that I normally would've not had to make and also just made them on my own. (P1)

Subthemes were identified in the theme of impact of caregiving and the implications of public health orders. The following six sub-themes and findings will be presented: isolation and loneliness, time away from work and the costs of the pandemic, visiting restrictions and forced separation, the risk of COVID transmission, stretching the rules, and lack of physical contact.

Isolation and Loneliness. Participants spoke of feeling alone and isolated in their caregiving and bereavement experience. Whether it was related to public health orders and restrictions, having limited supports in family or friends available, or feeling like they were just all alone in their experience, isolation and loneliness was experienced by several participants.

One participant shared “I felt like it was a very isolating experience”. Another participant spoke about the loneliness she felt in her bereavement experience. When asked about how it felt to grieve during the pandemic she said “lonely, lonely, lonely. Very hard. I mean, I’m still grieving. It was very hard... it is hard” (P3). The experience of feeling alone was also relayed by a participant whose loved one died early in the pandemic as an experience she felt no one she knew could relate to:

> I just feel like.. not that I would want anyone to relate to me but I felt like no one could possibly relate to me. Like I didn’t as it was, I really didn’t know of anyone who had had a family member in palliative care but then to have to do it by yourself like during the pandemic. (P1)

This reflects the unique experience caregivers had early on in the pandemic as they provided care and support to a loved one during unprecedented times.

Another participant shared “it was isolating and I’m not sure if it’s right but to say like.. I felt trapped in my own home that I couldn’t go anywhere” (P5). While participants loved ones were alive, participants shared how the pandemic and the restrictions created situations where they felt so alone and because of the pandemic, they weren’t able to receive supports that were available to them and this impacted the experience of feeling alone.

> I knew that my mom wasn't well and that it was.. right, time was not on our side and so, I just felt like everything was on me and so even though I was exhausted.. I still had to be that one person who was there for her and I couldn't really distribute the load. I think that was.. that was really, really, really tough for me because normally I would have been able to.. like with her sister, with friends but I couldn't do any of that because of the pandemic. (P1)

This caregiver spoke about how she had to trust and rely upon health care providers rather than friends and family:

> Because of the pandemic and lack of support I found that we had to solely reply upon the health care system rather than family and friends if that makes sense. I would have leaned on them [family and friends] a lot more but we had to rely on and trust basically health care professionals more than we would have in a regular situation. (P1)

Another participant spoke of being all alone right after her husband died at home and all of the staff left:

> Everyone left and I was totally alone. I constantly had at least eight people [staff] and then I had none. I had no family. Initially, I had friends but he died and they left. Everybody left. There was no one, absolutely no one for the simple reason that I mean everyone was trying to stay isolated. They're not going to be hanging around me and certainly they're not going to be hugging you or anything. (P2)

Time Away from Work and the Costs of the Pandemic. Participants shared that the financial impact was in the context of having to take time away from work. One participant shared "financially, largely it impacted me" (P4) while another participant spoke of how the situation of the pandemic resulted in her having to take an early leave from work "I decided to take a leave from my work and I think I took it earlier than I would have normally had there not been a pandemic" (P1). The financial impact wasn't only related to time away from work. One caregiver spoke of the financial costs that were associated with the pandemic:

> Monetarily... yeah, because you had to go through all these extra steps to you know to be able to see someone you know you had to buy the masks, you have to you know, get all the cleaning stuff and clean and time is money to me anyway, you know. (P3)

On the other hand, for a participant who was retired, she shared that she did not experience any financial impact but reflected that if she had been working, she would have retired:

> The pandemic did not impact me as a caregiver financially as fortunately I was retired. If I hadn't been retired I definitely would have you know, been putting in my notice because there was no way I would have worked through that. (P5)

Visiting Restrictions and Forced Separation. Although the magnitude of forced separation, visiting restrictions and overall, the public health orders, varied in the experiences of participants, all participants shared how they experienced on some level, the consequences of restrictions, separation, or overall public health orders. This impacted the caregiving experience in different ways. One caregiver shared that as a result of visiting restrictions their decision to remain at home was finalized:

> He didn't want to go to the hospital and that's what.. the thing that cemented the decision was COVID because sending him to the hospital would put him in further jeopardy and I would not be able to see him and he wanted to be with me when he died. (P2)

Another participant spoke about the impact visiting restrictions had on both her and her mother's safety as she relayed her experience of keeping her mom at home longer than she would have in a non-pandemic time:

> I was struggling so much with it and I was willing to actually put her safety and my safety at risk I guess you could say and keep her at home knowing that I might not be able to be with her in the hospital. (P1)

When participants loved ones were admitted to the hospital, participants shared the impact restrictions had on them:

> One of the examples that I will always remember is so my mom woke up she couldn’t breathe I needed to take her into the hospital and I remember having to just drop her off in a wheelchair at the doors of HSC [Health Sciences Centre] emerg [emergency] because they wouldn’t let me in with her. (P1)
>
> Like that was tough only having two people allowed in to visit, like how do you pick those two people? But luckily, that was only a month or so. So, when she was in her apartment, and I think restrictions changed, you were allowed more. But I think that's important to know, because for so many people… I just... that policy and the way it was enforced that certainly impacted a lot of families I think. (P4)

The impact of visiting restrictions and overall public health orders was not only experienced in the context of admissions to hospital. Participants shared how this impacted their experiences caregiving at home and specifically, how they were limited in who was able to visit their loved one. One participant shared “it was hard because she [mother] couldn’t have visitors you were limited to how many people you could have in the house so we as a family had to be very careful” (P3). This was a shared experience by another participant who explained her husband would have had more visitors in a non-pandemic time but he was able to connect with his friends in other ways:

> I know he probably would have had more visitors…. He had a lot of close friends and yeah I know he would have had more visitors. He got phone calls. Luckily he you know he had the strength. He talked on the phone. He would talk on the phone you know for an hour or more than an hour with a friend. So I'm very thankful you know at least he had his friends that still communicated even if they couldn't come and visit, they phoned him. (P5)

Restrictions impacted the ability for participants to be with their loved ones at appointments and one participant spoke about how devastating this was:

> There was appointments that I would have liked to have accompanied her with to but she had to go on her own and like even my dad wasn't allowed to go up and it was like holy, she's gotta be by yourself going through all this. It was just awful. We're a very close family and so to see someone you love go through so much pain... it's devastating. (P3)

As a result of not being able to be with her loved one, one participant shared that she felt she had to rely on hospital staff to give her updates because her mom was all alone during part of her admission:

> As challenging as it is during normal times without a pandemic but then relying on hospital staff to give you an update during the beginning of a pandemic is nearly impossible. So, that was very, very, very difficult. Knowing also that I couldn't be there with my mom in what were her final days at that point and she was alone in a hospital room receiving information and not information she wanted to hear right by herself. (P1)

The Risk of COVID Transmission. Participants spoke of having to deal with the risk of COVID transmission and how this impacted their caregiving experience. Two participants spoke about how they worried their involvement in the workforce, where they came into contact with other people, put their loved one at risk. One participant shared "It was hard because I was working and I was afraid to go near mom because I didn't want to get her sick. It was very difficult" (P3). Similarly, another caregiver shared:

> I was worried about getting COVID myself because I work in a hospital setting so I was worried about becoming sick and then not being able to care for my mom and I was also

> worried about giving it to my mom like potentially giving COVID to my mom. (P1)

The risk of COVID transmission was multifaceted and experienced not only by caregivers but also perceived as a concern staff had. One participant spoke of the different layers related to the risk of transmission and the worry she felt with health care aides working across different settings:

> I mean people [health are aides] were taking off because one aide [health care aide] had a pregnant wife and so he was worried about COVID from that point of view they're worried about it. So, I mean the COVID is you're dealing with.. you're worried about your husband, you're worried that you're going to get it, you're worried about your aides [health care aides] but they have.. they're going into how many different houses and it's a total misbelief to think that those agencies exist separate from personal care homes or hospitals. All of these people are working in two to three other places. (P2)

As a result of the impact the risk of transmission, caregivers felt they had to stay home and feared getting sick themselves and the impact this would have on their loved one:

> Due to the pandemic and [husband's] immune system being compromised; I was afraid to go out in public. Not only for fear of bringing something home to him, but for fear of me getting sick and not being able to provide him the care that he needed. (P5)

Caregivers spoke of feeling trapped in their homes because they were so worried about getting sick or passing COVID on to their loved ones but the need for a break or to get out of the house remained:

> Even for me to go out and shovel snow was a break. You know, I never thought that I would enjoy shoveling snow as much as I did but I had my cell phone in my pocket if [husband] needed me... you know, I shoveled snow here [her home] I went to my son's

> house and shoveled snow. But that to me was an outing. (P5)

Stretching the Rules. Despite the public health orders and overall restrictions, some caregivers spoke of how they made choices to knowingly break public health guidelines. One participant who struggled with not being able to hug her mom during periods of the pandemic shared “in the end, you know, we just cuddled and we hugged and we did what we needed to do and wanted to do” (P3). This caregiver spoke of how heartbreaking it had been to not physically hug her mom who she described as her best friend. Another caregiver spoke of stretching the public health orders the night that her mom died:

> The one thing that I remember actually the night mom died, we came together as a family and some of our kids have significant others they have been with six or seven years now. So, I think the night that mom died, we gathered at my son's apartment in [area of the City of Winnipeg] nearby, and I think we were one over the 10 people limit, you know by the time we add partners but you know, I’ll be very open that we cheated because it just made no sense. One person can’t be with us, you know. (P4)

A participant shared how meaningful visits were for her husband from his best friend even though the visits broke the public health orders:

> He would park his vehicle on the street you know, so there was never an extra vehicle parked in the driveway. So, if anyone you know, was out driving looking for houses with a bunch of cars in the driveway right they weren't going to see that. (P5)

One participant shared that although COVID had an impact on her bereavement experience, she felt that it did not change very much her caregiving experience “I don't feel like COVID changed a whole lot in my caregiving experience. Maybe more so my bereavement experience after but the things I did and the time I spent with mom... like COVID didn't influence that” (P4). This participant spoke of how whether there was a pandemic or not, COVID wouldn’t have impacted or changed what she did and the time spent with her mom as time with her mom was of most importance to her, regardless of the pandemic.

Lack of Physical Contact. Not being able to physically hug their loved ones, the lack of physical comfort or support from health care staff, and not being able to receive physical visits, hugs, or comfort during bereavement were all reported by participants. One caregiver spoke about how devastating it was to not be able to hug her mom:

> When you love someone you want to do whatever you can to help them. I loved my mother fiercely and it was just hard not being able to hug and do things that we normally would do that, you know. I don't know if I can elaborate it. It just.. it was the worst time of my life and the pandemic made it worse. (P3)

This caregiver also explained how her mother had an assisted death and when the MAID team came to the home and her mother died no physical touch or comfort was provided from the health care providers and the personal protective equipment made it feel sterile:

> They [MAID team] all came in with all their you know, protection gear and it just seemed so... ugh. Not that they weren't good. Don't get me wrong. They were amazing people but it was sterile and I don't know, just so many protocols to follow I didn't know what to expect but I would imagine that if it wasn't in COVID times that I don't know, you know, they [the MAID team] would have come closer to us at least you know, they might have hugged us. They might not have... hard to say but it just didn't seem very personal. (P3)

Public health orders prevented caregivers from being able to receive physical comfort and support during their grief:

> I had lots of phone calls. I had lots of flowers sent you know, neighbors would drop cards in the mailbox but yeah, it would have been nice to have that one on one. You know, have those hugs you know, just that. Yeah, a phone call is nice but you know, it's always... to talk to someone in person I find is so much better than.. especially in a circumstance like that. (P5)

This was also reported by caregivers in terms of counselling support and the preference for in person support with human contact:

> I really wanted to have counseling, but you know having it over the phone or via Zoom isn't just... you know. I was grateful but it didn’t cut it. It really didn’t. You need that human contact. So it was... it was... I felt like I was all on my own and you know what I had a fabulous social worker. She was great but would’ve been nice to do it in person. (P3)

Theme Two: Interrupted Grief and Commemoration During a Pandemic

All of the participants reported that their grief was affected in some way by the pandemic. Whether that was the result of having to wait to have a celebration of life or funeral, grieving alone or in isolation from supports, or by changes in funeral services, the data reflects that this was a key theme. Two sub themes were identified: delayed and difficult grief, and funerals or celebrations of life in COVID.

Delayed and Difficult Grief. The bereaved caregivers who participated in this study spoke of how their grief was not only different during the pandemic, but it was difficult.

> I think it honestly, like I was in a very dark place and I think it made me go to even a darker place. I just.. same thing I felt alone like in Judaism another example so typically you would sit what we call Shiva so it’s a seven-day mourning period right and that’s

> when you have friends and family surrounding you and just coming by to just check in and you know just really rallying behind the person and I couldn't do that so I just feel like it was more drawn-out.. the grieving process. (P1)

This illustrates how the ways in which caregivers received support, and cultural or traditional practices were interrupted as a result of the pandemic. One caregiver spoke of how difficult her grief was because she wasn't able to see her friends. She shared "well, it was difficult because I'm grieving... my friends... I've got lots of friends and they couldn't.... couldn't be with me" (P3). The impact of being at home, away from work, and not in a regular routine as a result of the pandemic was difficult:

> Maybe it weighed heavy I think normally I would have had you know probably had an easier transition. I hate to say what's normal grief or what isn't. But yeah, being home after, stuck at home after not being able to go to the workplace probably prevented me from kind of how you transition back to that normal busy you know things that fill your days a bit more. (P4)

When celebrations of life or funerals were delayed as a result of gathering restrictions, this resulted in an experience of delayed grief and impeded the opportunity to have closure. One caregiver shared "so I guess because it had been so long like it was kind of like opening up the wound again. Like that wound has was never healed and it still isn't. But just... we weren't able to have the closure" (P5). This caregiver shared her experience of having to wait to have her husband's funeral service as she was waiting for gathering restrictions to loosen. She spoke of feeling that there was a delay in getting closure and if it hadn't been for the pandemic, she could have had closure sooner:

> I just found too, in my grieving, even after [husband] passed, for me to have my friends

> who are all still married listening to them be happy... you know it would just set me off... to go into a grocery store and see couples together shopping was very difficult for me. I cried every day and I still cry. I don't cry every day but I still have my moments. Yeah, the grieving was very difficult and like I said I think if it hadn't been for the pandemic and we could have had that closure a little bit sooner and honored his wish. (P5)

Funerals and Celebrations of Life in COVID. Funerals and celebrations of life are usually a time where families can gather together to remember, honour, and reminisce on the life of the deceased. As a result of COVID, commemoration of loved ones through celebrations of life or funeral services was interrupted and changed. Gatherings were restricted and therefore, the ways in which people were able to hold services or celebrations was impacted. One participant shared that since her mother was private, their commemoration was not impacted by COVID but, after further reflection, she shared that she did feel they came together to honour her mom’s life differently:

> We grieved differently or we celebrated.. maybe celebrate isn’t the right word but we came together differently to say goodbye. And I think after you know, I hadn't thought about it when you asked the question but I would say it [COVID] probably did impact because I still wasn't seeing just my friends and my normal colleagues and things like that. (P4)

A participant spoke of how her mom was very involved in the community, she taught aerobics classes to seniors and was loved by many:

> We couldn't invite people to the funeral. My mom was so loved by so many people we had to put a maximum of 50 people and that was just family it didn’t even include all her friends and she was very, very big in the community. (P3)

Challenges with the restrictions regarding the number of people who could gather for a service was experienced by a caregiver who could only have 10 people in attendance of the service when her mom died:

> We had the pallbearers step away after they did what they needed to do and then they stepped away and kind of stood a little bit further so they wouldn't have counted as our 10 but I mean having to tell people that, and organize that was just awful. And then, telling people they couldn't come to the funeral. Like.. yeah it was again something I'll never forget. (P1)

For one caregiver, she spoke of having to wait 17 months to honour her husband's wish of a department funeral service and how meaningful it was for her to wait until restrictions would allow a large gathering but this extended her grieving process.

> He [husband] said when I pass I want the big departmental funeral service. There again with the pandemic, the limitations you know when they started opening things up the limitations of the number of people you could have we couldn't have the service that he wanted right away and I know I had a couple of my friends say to me well, if you can't like have that service, would you consider you know, just changing it like to a smaller group? And I said no way. No way. I will honor his wish and I will wait however long I have to wait until we can do that. So that really extended the grieving process for us. (P5)

Theme Three: Challenges with the Health Care System

A key theme identified in the data was challenges with the health care system. One caregiver captured this overall theme when she shared how COVID "just turned leaks into lakes" (P2). Caregivers shared their lived experiences which included several challenges and negative experiences and how some of these challenges pre-dated the pandemic but, the pandemic made it worse. Several sub-themes were identified: rotating staff, not enough services, negative experiences, COVID used as an excuse, and COVID making a difficult time harder.

Rotating Staff. Caregivers noted that there were staffing inconsistencies and their experiences reflected the challenges they had with staff who did not consistently see their loved ones. Although they had positive experiences with some staff, one caregiver explained that the next person may not be as good and they saw several different physicians in their home:

> The biggest problem was that every week you had a different.. I mean we did twice well maybe three or four times have the same doctor but they tried to they don't have you have the same one… which is a problem I think they [palliative care program] think because you have a supervisory nurse who she is very good but you can't run a system based on that person being very good because the next person may not be very good. (P2)

Inconsistent staffing resulted in caregivers reporting that staff weren’t able to see the changes in the person’s condition. One caregiver explained her experience with rotating staff. She spoke of the inconsistencies in assessments which impacted the health care provider’s ability to see changes in her mom’s condition. She shared “we never saw the same one hardly twice. So I felt like they were not seeing the changes in her” (P4). She spoke of larger systemic issues that may have impacted the inconsistent rotating staff. When the caregiver spoke of feeling that the care her mom received wasn’t patient or family focused, the student researcher asked the participant if she felt this was impacted by the pandemic and she shared:

> I think it made things worse and I think staff [were] under tremendous strain and so it's... we need to look at the system. So I'm not... I mean, I sort of am blaming individuals, because I'm really discouraged with the way mom was treated but we need to look at the root causes of why that is and how people are strained and why are you having 10

> different nurses come in. (P4)

This is an example which suggests that the strain on the health care system during the pandemic had a direct impact on caregivers who were providing care and support to their dying loved during the pandemic.

Not Enough Services. Caregivers spoke of needing more services than what was available or a delay in receiving the services requested. The Self and Family Managed Care Program is a program offered by the Winnipeg Regional Health Authority Home Care Program where clients or a family member can coordinate, manage and direct their own home care by employing their own staff with funding provided by the home care program (Winnipeg Regional Health Authority, 2023). This is a program one caregiver was part of while another caregiver had been in the process of arranging it but she explained that it took over a month to arrange. When services were finally available, her mom’s condition had changed so much that she needed to be admitted to the hospital.

> I ended up setting up family managed care like the home care piece for my mom but I definitely think it was delayed we actually only got services in place the night before she went into hospital for the last time. (P1)

The caregiver who was part of the Self and Family Managed Care Program shared that although she received some funding to cover some hours of care, she felt she needed 24-hour care for her husband and this was not provided. This participant shared that there weren’t enough services provided by home care. She had to supplement her husband’s care and paid out of pocket for this. Caregivers reported there weren’t enough bereavement services and supports available.

> As I said the hardest thing for me... and well palliative... even though they put me in care with their therapy people, there was no therapy being provided except I did have some

> Zoom [sessions] and they did provide me with six or eight weeks but there were just were not any resources in town for bereavement in general. (P2)

Negative Experiences. Negative experiences with health care staff and the health care system were reported by caregivers. This included experiences on a hospital unit, in the community, or negative experiences with programs and systems within health care.

One caregiver shared her experience with a nurse on the medicine unit where her mom died in the hospital. The caregiver was advocating for another visitor to be allowed entry as the caregiver, the daughter, was the only person allowed to see her mom. She shared that she will never forget how the nurse told her that her mom had to be imminently dying in order for another visitor to be allowed entry.

> I tried to advocate you know, asking for at least one other family member and they [hospital staff] wouldn't allow it. I remember the head nurse at one point said well, your mom has to be imminently dying so within 24 hours and to me you can't actually tell that.. there's absolutely no way. I work in health care and there's absolutely no way that you can determine that. Especially in that moment, I will remember that for the rest of my life. (P1)

She advocated for herself to have her husband there and she shared that he was finally allowed in on her mom's last day of life. The caregiver shared that the manager of the hospital unit told her she could have four more people come but at that point, the participant's mom had already passed away:

> I remember I was so angry because really, what was the point at that stage, right? And I know that my... like... I had spoken to my mom's sister... she didn't want to come at that point and same with my sister they didn't want to be there at that point [after the

> participant's mom had died]. (P1)

A caregiver spoke about her experience calling an evening nurse to come to the home when her husband wasn't doing well overnight. She explained that the nurse wasn't responding and didn't want to come to the home. That ended up being the night that the participant's husband died. She shared "I mean, that woman didn't come for hours and hours and I didn't know what to do and I felt totally abandoned by palliative at that point because of that woman and not responding in any meaningful way (P2).

In another situation, a caregiver shared the challenges she faced as she was advocating for her mom to be referred to hospice. She spoke of her experience where a palliative coordinator who told her she would complete the forms for hospice and the caregiver shared she felt relief to hear this but later that day, the plan had changed. The caregiver shared that a nurse who didn't know her mom came to the home. She didn't ask questions or do a thorough assessment but after the visit, the nurse called the coordinator and the decision was changed. The participant's mom was no longer a candidate for hospice and wasn't referred. She shared:

> So after that nurse left, she clearly called the coordinator and said oh, she's [the patient] not ready for the [hospice]. So [the coordinator] phoned me I was so disheartened and rudely honestly, this is what she said. She said, I'm ripping up those forms and... my heart just sank I was in my car and I, you know, after this whole hopeful day… (P4)

As the participant was explaining this experience she expressed her frustration and how disheartened she felt that based off of one assessment from a nurse who wasn't familiar with her mom, a big decision was made which directly impacted her mom and her mom's desire to be at hospice.

Being at home overnight without support physically present, was challenging for some caregivers. This was especially difficult when the administration of medications or medical interventions were required. A caregiver shared her experience feeling uncomfortable when she was alone overnight:

> I was here at night by myself when he had to have suction to breathe and I was supposed to be administering various kinds of drugs. There was no way I could do all that by myself and they [palliative care program] weren't providing me with any resources to do that and they had just during that day, given me new instructions and I was under a fair amount of stress and so I did not feel really comfortable with the changes that they made in terms of how I was supposed to be administering it. (P2)

Twenty-four-hour care isn't provided at home from the home care or palliative care programs and this pre-dates the pandemic. The pandemic did not change this. The lived experiences of caregivers who participated in this study illustrates the challenges that exist with managing symptoms at home without 24-hour support from trained staff.

COVID as an Excuse. Two caregiver participants spoke of experiences where they felt that COVID, and the pandemic, was being used as an excuse for attitudes, not providing care, or for lack of resources. This reflected the perspective that challenges existed prior to COVID but during the pandemic, COVID was used as the excuse. Two participants specifically spoke about this in the interviews. One participant shared her experience dealing with attitudes from some health care providers. She shared:

> I think [it's] partly pandemic because I think attitudes changed in health care. Like I think they [health care providers] used the pandemic to not be very kind sometimes and use it as an excuse. So whether it just puts... I appreciate the burden on staff, and it was it was hard. But yeah I think the attitudes weren't helped that way. (P4)

Another caregiver shared her experience with a particular staff member in the hospital when her husband went in for an operation. The caregiver shared her experience of being handed pamphlets with instructions on what to do but not being provided any hands-on support for managing the care after the operation. The caregiver shared she felt like COVID was an excuse for not providing the proper care:

> She [the health care worker] was concerned of course, about her safety and so COVID was an excuse for not providing us at all with any care and saying, go figure it out for yourself. I'm not gonna help you. So, she might have already you know, had certain reservations, but now she had COVID, which she could blame things on. (P2)

COVID as an excuse was reflected in another experience where a caregiver was seeking bereavement supports and the caregiver spoke of how it’s not necessarily only because of COVID why limited support were available. It is a result of lack of resources and funding. “It's not entirely COVID. Some of it is the lack of resources of money and stuff but again COVID was used as an excuse…” (P2).

Pandemic Making a Difficult Time Harder. Providing care to a loved one at end of life is a time that can be difficult for many. Caregivers in this study spoke of how COVID impacted the system and created further challenges. A caregiver explained:

> So, COVID enhanced everything and people were not prepared. I mean I think even now [November 2022] the regulations are constantly changing and no one.. no one knows what they're supposed to be doing. So, there's COVID as a disease you know, that's affecting that but there's COVID that is impinging on a whole system and how it operates. (P2)

Additionally, caregivers spoke of the effects COVID had on the caregiving experience.

One participant spoke of the added layers of stress COVID created with precautions at a time where herself and her family were already dealing with their mom's illness. She shared:

> You know, we took precautions and we did go to the home but yeah, it was sanitizing and I just remember you know, we've got our masks on, we've got gloves on, and we're sanitizing this food that has come to us, you know all the cans and it was just like holy shit we got enough on our plates.... (P3)

These excerpts from the data demonstrate how COVID and the implications of the overall pandemic made a difficult time harder and overall, amplified existing challenges that are present when someone is providing care and support to a loved one who is facing the end of their life.

Theme Four: People Make the Difference

The fourth key theme is people make the difference. Through the difficulties and challenges of COVID, caregivers shared several positive experiences during their journeys and it was clear that palliative care staff members made a positive difference.

Staff. One of the questions of the semi structured interview asked participants about their experience with the palliative care team. Caregivers reflected on positive lived experience with members from the interdisciplinary palliative care team. Two participants spoke about the nurses who saw their loved ones in the community, at home. They shared:

> The nurses who would come in daily, they were phenomenal and there were two that I can think of that were just went above and beyond and I can only imagine how difficult their job is to begin with and same thing, you add a pandemic and yeah they were just.. they were really wonderful. (P1)

> My experience with the palliative care team, they were absolutely fabulous and I don't

> know what I would... how I would have got through this journey without them. The nurses were all great. (P5)

Although caregivers reflected on the challenges they faced with some staff, specific programs and the health care system as a whole, one caregiver explained that palliative care as program was the best of what was available. “Palliative was the best of anything within the health system. It has the most resources and it should have the most resources. They were the only light in the tunnel” (P2).

Participants spoke of their positive experiences with the social worker both their own positive experiences but also the experience their loved one had:

> Mom's connection with [the social worker] was special. I am very grateful for her and the time she spent with mom and I was only present for a bit of that because I usually got out of the way and you know, gave them some space for those conversations. So I only... I kept hearing about [the social worker] and I really think I was only present for her last visit with mom and she's special. Her kindness and nonjudgement I don't think I can put into words what that meant for my mom. So plus plus gratitude for those visits they helped my mom a lot. (P4)

Similar sentiments were shared from another participant who saw the social worker for counselling support. She had expressed how hard her grief was and how the social worker supported her in her grief.

> I mean, the social worker was fantastic and really got me through my most difficult time in my life. My mom was my best friend and I've got lots of friends but not... not like her. So, the social worker was really helpful. (P3)

Some caregivers shared that caregiving during a pandemic was a very difficult experience, lonely, isolating, and added stress and challenges existed as a result of the pandemic. One caregiver spoke of how in all of this, she felt very supported by the palliative care team. "Being an end-of-life caregiver during the pandemic was very draining, but I knew I had 24/7 support from the team. They were there for me" (P5).

Theme Five: Recommendations Through Reflections

Caregivers provided recommendations throughout the interviews as they reflected on their experiences and shared lessons to be learned from the pandemic.

A Case for Change. Caregivers in this study shared in depth their experiences caregiving during COVID as well as their bereavement experiences. An important sub-theme that emerged from the data was a case for change. In speaking about their experiences there are important considerations related to change regarding how care and support is delivered and received.

In an earlier section of this chapter, the sub-theme of rotating staff was presented. Caregivers spoke of inconsistent staff and how this impacted their loved ones' care. One caregiver explained how a primary care model where a primary nurse sees the patient would be beneficial:

> I do think more of a primary care model or whatever you want to call it like a primary nurse to see your family on a weekly basis and build a relationship and be able to see the changes in that person over time I think would have gone a long, long way in the homecare program. (P4)

Caregivers spoke of how it would have been beneficial if staff stayed longer at each of their home visits. One caregiver shared her experience after everyone left her home after her husband died and she felt all alone. Another caregiver shared her experience after her mom had an assisted death:

> Mom went through the MAID process because she felt she didn't want to lose her dignity. You know, she was a very independent woman and if she couldn't do things on her own she didn't want anyone else doing them for her and so with that being said, going through the MAID process of course, I wanted to be there to support my mom but I didn't realize the trauma it would cause me when after the needle .. when she died, I was traumatized and I would just say to.. to the team that's there to stay as long as you can with the people, because it just seemed that you know, we were there when mom was dying, and we had our time but then shortly thereafter they left and it was really hard. It would have been nice to have the social worker stay longer and I know... I know the time constraints, but it would have been great to have them there a little bit longer" (P3)

This has important implications not only for MAID team staff, but all providers who are with caregivers when their loved ones die. Caregivers acknowledged the time constraints and demands on staff but this finding suggests there may be implications related to staffing and support that is needed at the time of death.

Another caregiver shared her positive experience she had with the palliative care physician but she noted that she didn’t meet him until the day her mom went to the hospital rather than when her mom was first enrolled on the palliative program or when she was at home and they were working to manage her symptoms:

> One thing that I feel like could have been done differently like the physician was amazing but we didn’t actually meet him until that morning of the 28th when he recommended that my mom go into the hospital so like there wasn’t that initial meeting I’m not sure if that’s changed but it would have just sort of been nice rather than just have the nurses talk to the doctor and do that. (P1)

Suggestions related to changes for the home care program were made: “my experience of getting into palliative care was through home care and home care and dealing with home care. I mean I'm glad we have home care but it is riddled with so many issues and problems and stresses (P2). This caregiver also explained how improvements could be made to the palliative care after hours supports that is available overnight:

> Home care needs so much restructuring, rethinking, it is a very bad situation in home care and the whole thing with palliative their problem is that if I had been sick, or even [husband] had been sick and if I had had to call at night, their system at night is horrible. (P2)

Another area regarding change expressed by participants was related to grief support. Overall, caregivers expressed that more grief support is needed and in particular, caregivers expressed a preference for in person support.

> After my mom did pass I did do some zoom sessions with [the social worker] that I found to be very helpful. I believe they were capped out at 10 sessions and that.. one of the things that I definitely could have used is more support. I don’t feel that 10 was enough. (P1)

There are lessons to be learned from the pandemic and one participant shared her thoughts regarding important learnings and takeaways from the pandemic. She spoke about balance and the importance of balancing the physical and biological needs with emotional and social needs:

> I think just as a system we have to.. and I hope that's what comes out of this a little bit is where was the balance like and could we do this better if, and it may happen again in our lifetime, like where we weigh the social needs as highly as the personal care needs, and spiritual/emotional as highly as safety and germ control. (P4)

> I hope there's still lessons learned with that stuff, even what was there was almost taken away from us by processes and protocols and rules and isolating and all that. And so I don't think it's just people that were in the dying process, but maybe concessions could have been made a bit looser for people and families who were in that process. (P4)

Summary

This chapter presented the findings of this qualitative phenomenological study which explored the lived experiences of bereaved caregivers during the COVID pandemic. Five key themes were found: impact of caregiving and the implications of public health orders, interrupted grief and commemoration during a pandemic, challenges with the health care system, people make the difference, and recommendations through reflections. Sub-themes within each theme were identified and the findings were reviewed in this chapter. This chapter included quotes from all participants and the five themes identified from the thematic analysis represent the entire data set.

Chapter 5: Discussion

This chapter includes a discussion of the findings of this qualitative phenomenological study. This chapter will discuss in detail, and analyze, each of the five themes and explore the implications of the findings. The existing literature relevant to the findings will be discussed throughout the chapter. Then, this chapter will consider this study's limitations, implications, and contributions to social work and finally, this chapter will discuss the recommendations for social work practice and education, for policy and the health care system, and recommendations for future research.

Theme One: Impact of Caregiving and the Implications of Public Health Orders

The rich narratives provided by the bereaved caregivers in this study identified a primary theme related to the impact of caregiving and the implications of public health orders. Initially, the student researcher had identified these as two separate themes but as data was analyzed and reviewed, it was clear that these two themes were very interconnected. The data related to the impact of caregiving also reflected the implications of public health orders and therefore, one theme was created with several sub-themes.

Isolation and Loneliness

Bereaved caregivers in this study spoke of feeling isolated and lonely. Participants shared they felt lonely and isolated in their caregiving and bereavement experience. As a result of public health orders, social distancing, and restrictions, caregiving and grieving during the pandemic felt lonely and isolating.

The pre-pandemic literature reflects that caregiving at EOL can be emotionally straining and sad (Johansson & Grimby, 2012; Lai et al., 2014). The literature that has been published during the pandemic supports the finding of isolation and loneliness. The experience of feeling isolated was reported across several studies (Nyblom et al., 2022; Sousa et al., 2020; Wind et al., 2022).

Wind and colleagues found in their 2022 study with family caregivers of non-COVID patients, that caregivers isolated themselves at home and as a result of limited social interactions, caregivers felt lonely. Although isolation and loneliness were not identified as one of the four themes in Wind and colleagues (2022) study, caregivers spoke of experiencing restricted social contacts and emotional despair which was related to the study's themes of dealing with the risk of transmitting COVID to the patient.

In their study with caregivers for individuals with end-stage renal disease, Sousa and colleagues (2020) found that caregivers reported a decrease in interactions with other family members who pre-pandemic, would help with caregiving needs. The researchers explained that this left the caregivers feeling isolated and without support (Sousa et al., 2020). Similarly, Nyblom and colleagues share in their 2022 study which included both palliative care patients and their caregivers, that participants felt distressing fear and were left feeling lonely and depressed.

Doing it all by yourself, feeling trapped at home and isolated, not being able to distribute the load, and feeling lonely while grieving were all experiences reported by participants in this thesis study. The finding of isolation and loneliness is consistent with the literature. It's clear from these findings that the experience of isolation and loneliness was prevalent amongst EOL caregivers during the pandemic and this finding is supported by the literature.

Time Away from Work and the Costs of the Pandemic

Caregivers shared their experiences of being financially impacted whilst caregiving during the pandemic. Three of the five caregivers shared they were financially impacted as a direct result of the pandemic. The literature review discusses the financial impact of caregiving.

It is well documented in the pre-pandemic literature that caregiving at EOL can have a negative financial impact on the caregiver (Chi et al., 2018; Gardiner et al., 2014; Gustavson & Dal Santo, 2008; Williams et al., 2015). One caregiver in this current study spoke about how she took an early leave from work as a result of the pandemic. Taking time away from work was experienced by caregivers pre-pandemic. The literature reveals that caregivers have to temporarily stop work or reduce the number of hours worked (Stajduhar, 2013).

The literature related to COVID upholds the findings of this study. In Cross and colleagues 2022 (p. 253) study with family caregivers of end-stage-heart disease patients, 36.3% (n=113) of caregivers reported a change in their everyday routine and for some, this was a change in their work and financial situation. One caregiver in this thesis study spoke of the financial costs associated with the pandemic including masks and cleaning supplies. Family caregivers shared that they experienced financial constraints and participants spoke of the difficulty they experienced in getting supplies (Cross et al., 2022). In another study, participants shared that they worried about loss of employment, loss of income, and COVID “exacerbated this stress” (Lightfoot et al., 2021, p. 11).

Gardiner and colleagues found in their 2022 study, family caregiving at EOL has a significant impact on the caregiver’s employment. The data collected for their study was from 2017-2018. This is important to note as it demonstrates how the financial impact and time away from work was experienced by caregivers pre-pandemic. With the added impact of COVID, and the findings of this study, this is an area that could be researched further to explore how EOL caregivers were further impacted in regards to their employment and financial situation.

Visiting Restrictions and Forced Separation

Restrictions and forced separation impacted the participants in this study in different ways. All participants shared how they experienced on some level, the consequences of restrictions as it related to visiting, forced separation, or the fear of forced separation. This finding is consistent with the literature. Lightfoot and colleagues (2021) explain that the most common concern family caregivers reported was related to the separation created by quarantining and physical distancing. Participants spoke of forced separation and the impact this had on their loved ones' mental and physical well-being (Lightfoot et al., 2021).

In this thesis study, caregivers shared they worried about hospitalization as they would be separated from their loved one as a result of restrictions. This is consistent with the experience shared by caregivers in another study where one caregiver reported how distressed she felt when her husband was admitted to the hospital and she felt helpless as she worried he would die alone (Sannes et al., 2020).

In this thesis study, only one participant's loved one died in hospital. All other participant's loved ones died at home. The literature reflects the challenges families experienced with visiting when their loved one was admitted or institutionalized at the time of their death (Becqué et al, 2022; Guité-Verret et al., 2021; Hanna et al, 2021; Lightfoot et al, 2021; Plunkett et al., 2021). This is consistent with the experience of one participant in the current study whose loved one died in a hospital and she was met with several challenges which is reflected in the findings chapter. Existing literature reflects how the visiting rules didn't fit all families. One caregiver in a recent study shared how only one adult child would be allowed to visit but the caregiver and their terminally ill spouse had six children (Becqué et al, 2022). When families had to "bear the burden of who to allow in the home" it resulted in fewer visitors and in turn, less support (Gergerich et al., 2020).

Further research into the area of visiting restrictions at EOL and the experience of caregivers across a variety of settings (hospital, palliative care unit, hospice, and long-term care) is needed in a Canadian and Manitoban setting. Some studies report that caregivers were not able to physically be with their loved ones as a result of restrictions and goodbyes were said through a window (Hanna et al., 2021) or over the phone (Becqué et al, 2022). Although all participants in this study experienced the effects of visiting restrictions, they were not separated from their loved ones when they died. Being separated from your loved one at time of death is an area that could be further explored.

The Risk of COVID Transmission

Worry and fear regarding the transmission of COVID was reported by participants. In several instances caregivers were concerned they would give COVID to their loved one or, they would get COVID, get sick, and not be able to provide care. This is not a surprising finding as COVID was described as the most challenging public health situation and first vaccine doses weren’t available to health-care workers until December 2020 (Government of Manitoba, 2020). It’s not surprising that caregivers would be worried about getting COVID at a time when the pandemic was new, within its first year, and there were many unknowns. Four of five participants spoke of the worry or fear related to COVID transmission and the other participant spoke of how careful her mom was with COVID and how her mom took precautions so she wouldn’t pass along COVID to any of the staff who entered the home.

The worry and fear regarding the transmission of COVID is supported by the literature. Caregivers feared they would become contaminated with COVID (Becqué et al, 2022) while some caregivers experienced “distressing fear” which was “related to the risk of infecting the patient” (Nyblom et al., 2022, p. 4). For family caregivers who didn’t live in the home with the patient, they reported that this had a significant impact on them as they felt they had to stay away to protect their loved one from potential infection (Wind et al., 2022). This is consistent with the experience of one caregiver in this thesis study who shared how difficult it was to stay away from her mom who lived in another household.

Regardless of the location of death, dealing with the risk of COVID transmission was reported by caregivers in the current study. This resulted in caregivers experiencing increased fear and worry.

Stretching the Rules

Some caregivers spoke of breaking the public health orders and stretching the rules. Instances of this included cuddling and hugging when physical distancing was recommended, having visitors in the home when they weren't allowed, or exceeding the gathering limits. In the extensive search of the literature for this study, the student researcher found only one study where caregivers spoke of breaking the rules. Caregivers shared "the need for comfort outweighed the lockdown restrictions that were in place as a result of the pandemic" (Hanna et al., 2021, p. 847). In another study, a caregiver spoke of returning from a trip and the difficult decision she had to weigh, see her mom and risk transmission or not seeing her mom and risk not being able to say goodbye (Wind et al., 2022).

The area of stretching the rules may be a gap in the literature and an area to further explore. It's important to consider that the experience of stretching the rules may be more prevalent than how it's reflected in the literature. Discussing breaking public health orders may not be a topic many caregivers feel comfortable sharing as it can be a polarizing topic but now that public health orders have changed, caregivers in this study may have felt more comfortable sharing their experiences with breaking the rules.

In a study which explored social workers perspective and experiences working with patients and families at end of life, it was reported that although public health orders including "limiting visitors in the home helps prevent potential infection, it may result in a decrease of social support" (Gergerich et al., 2020).

What is known, is that EOL is a time of emotional strain and distress and for some families, finding balance at EOL may include stretching the rules to provide support, care, and comfort. The findings of this thesis confirms that caregivers did in some instances, stretch the rules during the pandemic.

Lack of Physical Contact

COVID introduced a time where social and physical distancing was the new normal. Staying safely apart was noted as one of the fundamentals of living with COVID (Government of Manitoba, 2020). Bereaved caregivers of the current study shared that they lacked physical contact with their loved ones, with staff, and with their support system. A caregiver spoke of how devastating it was to not hug her mom while another shared her experience of receiving support in the form of calls and cards when her husband passed wasn't the same as receiving support in person. Another caregiver of the current study spoke of her experience with staff and wanting a hug or comfort from staff who were present when her mom died. Although counselling support was appreciated, it didn't feel as personal virtually without human contact. The opinion of virtual supports as inferior to in person support was also reported by health care providers. Palliative care practitioners stated that virtual visits "were sometimes inadequate to foster therapeutic relationships considered integral to the delivery of palliative care" (Government of Canada, 2021, p. 19). This finding from the Government of Canada's report on community based palliative care during COVID supports the current study's finding that virtual support did not feel as personal as in person, physical support.

The finding of the lack of physical contact as a prevalent experience amongst bereaved caregivers is supported in the literature through the lived experiences of other caregivers. In their study which explored expressing grief through metaphors with bereaved family caregivers, participants spoke of being cut-off and this metaphor included experiences of being cut off from physical touch such as a warm embrace (Guité-Verret et al., 2021). Similarly, in a study exploring dignity reflections of EOL caregivers, participants spoke of not being able to embrace their loved ones (Becqué et al, 2022). The findings of the current study and the literature reveals how important it is for caregivers to physically embrace and be physically present with their loved ones at end of life. Finding a balance will be discussed in further detail in subsequent sections of this chapter.

Theme Two: Interrupted Grief and Commemoration During a Pandemic

The bereaved caregivers in this study spoke of experiencing delayed, difficult grief, and they spoke of how the public health orders directly impacted how they celebrated or commemorated the lives of their loved ones.

Delayed and Difficult Grief

Bereaved caregivers shared experiences of dealing with delayed grief and overall, experiences of difficult grief during the pandemic. Participants spoke of how the pandemic impacted their grief in a negative way. Instances of this included participants speaking of how they were in a dark place in their grief and the situation of the pandemic made them go to “even a darker place” (P1). They spoke of experiencing a drawn-out grieving process, grieving without the presence of friends or family around, and not getting closure.

The sub-theme of delayed grief is represented in participants’ experiences of having to wait to commemorate their loved ones and for some participants, this, in combination with being isolated from support systems, resulted in a difficult grieving process. This finding is supported by the literature. The pre-pandemic literature documents that the experience of complicated grief is prevalent amongst the survivors of the deceased. The literature review chapter of this document noted that 10-15% of bereaved caregivers struggle with adapting with their grief (The Center for Prolonged Grief, 2023). The Center for Prolonged Grief is located in the United States. The research that has emerged since the pandemic also reflects the prevalence of delayed and difficult grief as a result of the pandemic. Bereaved caregivers in a 2021 study spoke of how their grief differed from other grief they experienced and explained that “you know, basically what we’re going through is not just grieving it’s grieving in a pandemic” (Guité-Verret et al., 2021, p. 8). In this thesis study, the researcher did not ask participants about how their grief during the pandemic compared to other experiences they’ve had with grief. In Guité-Verret and colleagues (2021, p. 7) study, which looked at expressing grief through metaphors, participants spoke of how the social confinement of the pandemic added difficulty to their grief and the metaphor of “obstruction in grief” related to the experience participants had of “blocked or suspended grief”. This is consistent with the finding of this thesis study where caregivers experienced delayed and difficult grief as a result of the conditions of the pandemic.

Compared to men, women are higher risk to experience complicated grief (The Centre for Prolonged Grief, 2023) and several studies found that spousal caregivers are at high risk for complicated grief (Bruinsma et al., 2015; Nielsen et al., 2017a). All of the participants in this study were women and 2 were spouses. Although all participants reported the pandemic impacted their grief in some way, some caregivers reported particularly difficult grief. Their reports of their experience of grief would meet criteria for complicated grief while others did not. Therefore, as a result of the differing experiences related to difficult and complicated grief, this study does not make any conclusions regarding the prevalence of difficult or complicated grief specific to the caregivers gender or relationship to their deceased loved one.

Overall, the literature supports the finding of delayed and difficult grief as a prevalent experience amongst bereaved caregivers and the negative impact COVID has had in their bereavement experience.

Funerals and Celebrations of Life in COVID

The circumstances of the pandemic and associated public health orders had a direct impact on funerals and celebrations of life. Participants in the current study were negatively impacted by these restrictions. Caregivers experienced different challenges related to funerals and celebrations of life. One daughter spoke of not being able to include her mom's friends at her service while another caregiver had to wait nearly a year and a half to have the service her husband asked for. A daughter was burdened with having to plan a funeral of only 10 people and had to tell people they couldn't come.

The pandemic impacted the way caregivers grieved, celebrated, and commemorated their loved one. Grief was prolonged as a result of delayed funerals and grief was complicated as a result of funeral and memorial gathering restrictions, and being cut off from support networks. These findings are corroborated in the emerging literature on COVID, funerals, and celebrations of life. As a result of the pandemic and restrictions, grieving caregivers experienced "delay of burial, an inability to gather for funeral services/rituals, and restrictions on number of attendees for services/rituals" (Gergerich et al., 2020, p. 8). This is supported by Holland and colleagues (2020) who explain that as a result of COVID, funerals and memorials were delayed and when allowed, there were requirements regarding attendance.

None of the caregivers in this thesis study reported to experience a virtual funeral or celebration of life for their loved one. The emerging literature explains that virtual funerals were reported by bereaved caregivers to feel incomplete (Guité-Verret et al., 2021). Although some of the caregivers in this thesis study had an in-person service, they spoke of the limitations in the number of attendees and this can also be related to a feeling of incompleteness. One caregiver when speaking of her mom's limited funeral stated that it was "something I'll never forget" (P1).

Theme Three: Challenges with the Health Care System

This study of lived experience found that challenges with the health care system was a key theme. Rotating staff, not being provided with enough services, negative experiences in interactions with health care staff, COVID used as an excuse, and COVID making a difficult time harder are all sub-themes identified within this theme.

Rotating Staff

Two caregivers in this study spoke of the challenges they experienced with inconsistent, rotating health care providers at home. Caregivers' lived experience reflects the negative impact rotating and inconsistent staff had on the care of their loved ones. Caregivers felt this resulted in inadequate assessments on their loved one's condition and one caregiver suggested there are larger systemic issues that have resulted in staff who are strained.

In the review of the emerging literature on COVID, the student researcher was unable to find literature which specifically supports the finding of rotating, inconsistent staff as it relates to the experiences of caregivers. This may be because the pandemic is still a newer area of research and the experience of bereaved caregivers and challenges with the health care system is on its own, a niched and new area of study.

The existing literature supports the finding that the health care system during COVID was strained, and as more people died at home rather than in a hospital setting, caregivers were burdened with further responsibilities as services were limited. This is explained in the Government of Canada's report on home and community-based palliative care during the pandemic. The Government of Canada (2021, p. 22) reported that as more people shifted care to the home setting rather than in an institution, "this shift had a profound impact on the expectations placed on caregivers in the home, particularly given the scarcity of in-home palliative care services". It is possible, that the strained health care system resulted in limited staff available and therefore, it resulted in challenges in providing consistent visits from the same health care providers in the community. The Government of Canada (2021, p. 13) also state that "sickness, burnout and pay inequity across health care sectors further contributed to staffing shortages". Staffing shortages and overall challenges related to the lack of services will be discussed next.

Not Enough Services

Caregivers reported needing more services than what was provided or having to wait for services so long that when it was ready, their loved one was admitted to the hospital and it was too late. Caregivers also spoke of feeling that there weren't sufficient grief supports available. Living with modified specialized palliative care was one of the themes found in a 2022 study where palliative care family caregivers were interviewed (Wind et al., 2022). Caregivers reported that home visits were canceled which left them feeling abandoned (Wind et al., 2022) and in another study, a caregiver reported their palliative home care services were delayed as a result of the pandemic (Gerlach et al., 2022). This is consistent with the data from the Canadian Institute for Health Information (n.d) where home care assessments were measured. The data demonstrates that home care assessments declined significantly during the first wave of the pandemic (Canadian Institute for Health Information, n.d).

In the Government of Canada’s report, they explain that health care professionals reported that staffing challenges influenced their ability to provide palliative care services (Government of Canada, 2021). The findings regarding the escalating pressure on the health care system and on palliative care services is consistent. In a UK study (n=277), researchers found that 26% of palliative care providers interviewed reported they were “a lot more busy” during the pandemic and 22% felt they were “slightly more busy” (Sleeman et al., 2022). This study included palliative care providers from a variety of settings and therefore was not specific to home-based care, but this illustrates the impact COVID had on palliative care providers. Sleeman and colleagues (2022, p. 466) also found that hands on or home-based palliative care services “had greater odds of being busier than services that did not provide care in these settings”.

The pandemic impacted home and community based palliative care and “organizations that provide community support services to people with palliative care needs and their caregivers were closed or changed the way their services were provided” (Government of Canada, 2021, p. 5). The increased pressure and demand on health care services and specifically, home based palliative care, supports the findings of this study. These findings inform the recommendations of this study. Consistent staff, more bereavement support, and stable, enhanced community-based staffing resources are needed.

Negative Experiences

Challenges with health care staff and the health care system were reported by participants. Some caregivers spoke of specific negative experiences with health care providers. Instances of negative experiences reported were with community-based palliative care providers while others were with hospital-based staff on an acute care unit. One bereaved caregiver spoke of her interactions with a nurse when her mom was admitted to the hospital. The nurse informed the caregiver other visitors weren’t allowed yet as her mom had to be imminently dying within 24 hours. She spoke of her frustration and anger she felt towards the nurse and the nurse manager. By the time they allowed other visitors, her mom had already died. Similar experiences are echoed in other studies with caregivers. Hanna and colleagues (2021, p. 848) reported that caregivers who had a loved one admitted to the hospital or in long term care wanted to be with their loved ones in the final days of life but health care providers informed them “we’re not at the end yet” and caregivers explained that by the time they were told it was imminent and they could visit, it was too late and they weren’t able to say goodbye.

Communication which is empathetic and compassionate is always important in health care. The experiences shared by participants in this study and in experiences reported in the literature reflect how crucial it is for health care providers to always be compassionate in their communication especially in the most difficult of times such as a pandemic. Without this compassionate communication, caregivers could be left with a negative memory of staff. For one participant she shared that her negative experience with the nurse in the hospital when her mom died is something she will “never forget” (P1).

Power imbalance was experienced by family caregivers in Gerlach and colleagues (2022) study. Similarly, a caregiver in the current study spoke of how she felt the health care team had a “paternalistic attitude” (P4).

Participants in the current thesis study spoke of negative experiences with staff as it related to overnight support. Caregivers were left feeling abandoned by staff at night and felt uncomfortable and stressed when they were left on their own to provide care without resources, guidance, and support. The sub-theme of negative experiences with staff and the health care system is not a surprising finding. It is well documented that pre-pandemic, end of life is a stressful time for family caregivers and COVID put greater strain on both caregivers and the health care system.

In the current study, two of the participants who spoke of specific negative experiences with staff shared that they themselves, have a background in health care. This dual lived experience of being a caregiver while also having a background as a health care provider is an area of research which would benefit from further attention in the context of the pandemic. Some participants shared they felt their negative experiences were related to issues with the system and lack of resources while others felt their negative experiences were the result of the pandemic and associated restrictions. Given the small sample of this study and that the root of negative experiences was not particularly explored in depth, this is another area of research worth exploring further. This would create an opportunity to understand the causes of caregiver's negative experiences. This section has discussed the challenges related to staffing, services, and the difficulties with the COVID pandemic making a challenging time, harder. It is not surprising that this would result in caregivers reporting frustrations, anger, and overall, negative experiences with some health care providers and the larger health care system as a whole.

COVID Used as an Excuse

The finding of COVID being used as an excuse by health care providers was found in the experiences of two participants. This was reflected in their experiences with staff. Caregivers reported they felt the pandemic was used as an excuse for attitudes and for not providing proper care. In essence, caregivers reported that some of the challenges they encountered weren't necessarily a result of the pandemic, but the pandemic was used as a scapegoat. Participants shared "I think they [health care providers] used the pandemic to not be very kind" (P4) and

"COVID was an excuse for not providing us at all with any care…" (P2). This is a finding that isn't explicitly discussed in any of the literature the student researcher reviewed as it related to the experiences of EOL caregivers. The literature does reflect the burnout experienced by health care workers which Affleck & Wagner (2022) explain pre-dated the pandemic. They state this burnout is the result of "structural determinants of burnout at a system level that are driving service-level health workforce burnout in Canada" (Affleck & Wagner, 2022, p. 243). The authors explain that the structural issues in the health care system, has impacted the health workforce and has caused burnout (Affleck & Wagner, 2022). This is an area which requires further exploration. How has the burnout amongst health care providers impacted their interactions with family caregivers and patients? How has this impacted the caregiving experience? The findings suggest that in interactions with health care providers, some caregivers felt COVID was used as an excuse. There were minimal instances reported of this overall in the data but this is a noteworthy finding which should be explored further.

A caregiver shared she felt that the challenges regarding resources and the experience of not being provided sufficient community-based supports was "not entirely COVID. Some of it is the lack of resources of money and stuff but again COVID was used as an excuse" (P2). The data reflects that the challenges with community-based home care pre-dates the pandemic. In a Statistics Canada report it was revealed that in 2015/2016, 35.4% of individuals had unmet home care needs and individuals who lived with a partner, and those with an income under $39,000 were more likely to have unmet home care needs (Gilmour, 2018, p. 9). This data from Statistics Canada demonstrates that the challenges with inadequate home care services is an issue which pre-dates the pandemic and recent literature suggests the pandemic strained an already straining system.

COVID Making a Difficult Time Harder

It is well documented that caregiving at EOL is all-consuming (Breen, et al., 2018). Caregivers play multiple roles and juggle multiple responsibilities which can result in an overall feeling of burden which negatively impacts the caregiver's well-being (Bialon & Coke, 2012; Williams et al., 2015). The study explored if the pandemic impacted caregivers and if so, how did it impact them. Caregivers spoke of how challenges with caregiving were amplified by the situation of the pandemic.

Caregiver burden and the overall impact of caregiving at EOL has been documented in the literature (Anderson & White, 2018; Bialon, & Coke, 2012; Olson, 2014; Stajduhar, 2013; Williams et al., 2015). Caregivers spoke of how COVID enhanced everything. COVID impacted the system and how care was delivered and it increased the burdens and stress placed on caregivers. It is documented that caregiver burden increases throughout the caregiver journey (Guerriere et al., 2016). A participant in this thesis study spoke of the added stress the pandemic created. She spoke of the precautions, the personal protective equipment, and the worry associated with transmission. She shared "…it was just like holy shit we got enough on our plates" (P3). The literature supports this finding of COVID increasing caregiver stress, burden, and overall how the pandemic amplified an already challenging time for caregivers.

The findings of this study suggest that caregiver burden increased as a result of COVID. In a study of 835 participants, 55.7% reported increased caregiving intensity and 53.1% reported increased caregiver burden as a consequence of the pandemic (Cohen et al., 2021, p. 3). The researchers found that the prevalence of caregiver burden as a result of COVID amongst females was higher at 56% compared to males at 52% (Cohen et al., 2021, p. 3). Contrary to this, researchers in another study found that objective burden (hours spent caregiving) did not increase on average over the pandemic while subjective caregiver burden had only slightly increased (Gräler et al., 2021). Researchers did find that women were one of the cohorts of caregivers who were more likely to experience an increase in caregiver burden during the pandemic (Gräler et al., 2021). Both of these studies were not specific to end of life caregivers. Participants for both studies were informal caregivers providing care to individuals with a variety of health conditions and therefore it cannot be presumed these findings represent the caregiver burden experienced by EOL caregivers. The findings of this thesis study support the notion that caregiver burden increased for EOL caregivers during the pandemic. EOL caregivers are a particular cohort of caregivers with experiences unique to dying. This is an area where further research is required to learn more about the how the pandemic amplified the challenges experienced by EOL caregivers and how this increased burden impacted grief. This study found that all five participants experienced difficult and delayed grief.

Theme Four: People Make the Difference

Through all of the challenges, frustrations, and the negative implications of the public health orders, caregivers in this study spoke of positive experiences with staff and how they made a difference in their experiences.

Staff

Caregivers shared their experiences of positive interactions with interdisciplinary palliative care staff including specifically palliative care nurses and social workers. Caregivers also spoke overall about positive experiences with the palliative care program.

The findings chapter illustrated how caregivers felt lonely, isolated, and stressed. One caregiver shared that in her draining experience she felt support from the palliative care team and she doesn’t know how she would have gone through what she did, without them. The theme of positive experiences specifically with health care providers, is reflected in other studies. Researchers identified that “compassionate professional support” was a theme in their study which supported dignity of patients and families (Becqué et al., 2022, p. 777). This was reflected in experiences where “dignity was preserved by being loved by the nurses and taken care of with affection” (Becqué et al., 2022, p. 777).

Although positive experiences with staff is a theme in the emerging literature, studies often report both positive and negative experiences (Becqué et al., 2022; Gerlach et al., 2022). This is consistent with the current thesis study in which caregivers had varied experiences. For example, one caregiver specifically spoke of how she felt supported 24/7 by the palliative care team while another participant shared she felt completely abandoned by the palliative care team overnight. For some caregivers, their experiences with staff were predominantly positive, others were predominantly negative, and some were mixed. This demonstrates the unique experiences of caregivers. Further research is required to delineate if certain experiences are related to a particular time during the pandemic, the care needs and resources available for the patient, or particular caregiver circumstances.

Theme Five: Recommendations Through Reflections

Throughout the interviews, caregivers reflected on their lived experiences caregiving and grieving during the pandemic. Through their reflections, they shared several recommendations.

A Case for Change

Important considerations regarding change was a sub-theme found in the data. Caregivers provided detailed examples of varied experiences. Several caregivers made suggestions for change in how care and support is provided and changes to how policies are enforced. A main purpose of this study was to learn from family caregivers. Participants made several suggestions which included: for health care providers to “think outside the box” (P1) and provide person centered care. This was echoed in other suggestions by participants who felt a primary model of care with consistent staff who would get to know their loved one and build a relationship with them is needed. A participant spoke of how beneficial it could be if health care providers could stay longer post-death and offer support. An opinion shared by several participants was that more bereavement support is needed and there was a strong preference for in-person support. Overall, a case for change was made and caregivers spoke of needing consistent staff, more bereavement support, and stable, enhanced community-based staffing resources. Flexibility in rules regarding visitation and commemorations is needed.

The challenges experienced by participants in the study are corroborated by palliative care providers. In their report on home and community based palliative care, interviewees “highlighted the impacts of chronic funding shortfalls and increased fragmentation of home and community-based palliative care services” (Government of Canada, 2021).

Through the sharing of their lived experiences and as caregivers spoke of their challenges, it is observed how there is a need for change in policy and public health orders should society encounter another pandemic. These specific recommendations and the implications this has for social workers and other health care professionals will be discussed in a subsequent section.

There are important lessons to be learned from the participants in this study and in the findings. A primary lesson which captures the lived experiences of study participants is the need for a balanced and holistic approach in palliative EOL care at all times and especially in times of a pandemic. There are crucial lessons to be learned regarding policies. Visitation policies, gathering restrictions, and overall public health orders must have more flexibility for EOL situations. Plunkett and colleagues (2021, p. 4) state “more than ever, during this unprecedented time, there is a need to incorporate psychosocial needs in a more humane, person-centered care equation”.

Unique Experiences

Notwithstanding the challenges created by COVID and the overall implications of the pandemic, one caregiver shared her unique perspective regarding the pandemic and how in some ways, it was a blessing:

> So maybe the pandemic was a bit of a blessing in a way too, you know, how life just slowed down and you were able to [work from home] in your sweats or whatever. Those things it was probably a mixed blessing in some way I think for a lot of us just to change the pace of our normal lives for a bit. (P4)

The participant shared this perspective in the context of her work and how it changed to remote work and she no longer had the demands of a commute or getting ready. The participant also shared how COVID created a situation where herself and her family were at home more and this resulted in them being able to spend more time together. She shared that she felt as time went on, it moved away from being a blessing:

> Initially in the beginning it was first a blessing but I think over time you know that took its toll to not being in the workplace and not socializing with colleagues and yeah... yeah I would say in the beginning, maybe a blessing but as it went on and seeing the effect it had on the kids who really need to socialize. (P4)

Although this perspective was only shared by one participant and it is not included as a theme it’s important to include this unique experience as this study aims to represent a full picture of the entire data set which includes varied lived experiences from different caregiver participants.

One study found in the review of the literature addresses the “silver linings” and what the authors describe as the benefits of caregiving during COVID (Lightfoot et al., 2021). This study spoke of concerns caregivers had as well as benefits. Researchers identified five themes related to the benefits of caregiving during COVID which included a “slower pace, increased time to spend together, deepened relationships, recognized resilience in family members, and caregiving innovations” (Lightfoot et al., 2021, p. 12). The researchers specifically asked participants, what did they consider the benefits of being a caregiver during the pandemic. This study was also not specific to only EOL caregivers. The results of this thesis study may have included additional silver linings of COVID if the researcher had specifically asked participants this question.

Although the experience of COVID as a blessing was experienced by only one participant in this study, it is important to discuss as it “captures something important in relation to the overall research question” (Braun & Clarke, 2006, p. 82). The research questions explored caregiver’s lived experiences and did not specifically ask participants about positive or negative experiences. Including this in the discussion is important as it helps to support a representation of the data and all lived experiences of participants.

Summary of Discussion of Findings

This study contributed to a new and emerging area of research as it relates to end of life, caregiving, bereavement, and the COVID pandemic. The findings of this study illustrate the profound effects public health orders had on end-of-life caregiver’s caregiving experience as well as their bereavement experience.

The pandemic impacted the caregiving and bereavement experiences of participants in different ways. For some caregivers, they report it was the worst time of their lives and an experience that changed them forever. For another caregiver, she felt the pandemic impacted her grief but did not impact her caregiving experience. This finding of the varied impact the pandemic had on bereaved caregivers is similar to the findings of Wind and colleagues (2022) study with palliative care family caregivers. They stated that "for some family caregivers, the pandemic had a radical impact on their lives, while for others it was less significant" (Wind et al., 2022, p. 5).

The literature review chapter discussed how the key areas identified in the review are interrelated. This is also observed with the findings of this study. Themes and sub-themes are interrelated. For example, experiences of isolation and loneliness were expressed in the context of visitation restrictions and forced separation. The risk of COVID transmission was for some participants, related to experiences which illustrated difficulties with the lack of physical contact. In some instances, negative experiences with staff were in the context of visiting restrictions. Difficulties in grief for some participants related to not having enough bereavement services or delays and changes to funerals. These examples illustrate the importance for social workers and all health care providers to consider all of the circumstances and factors which impact the caregiving experience. A holistic approach with caregivers is required. The ways in which the COVID pandemic impacted caregivers is multifactorial and interrelated.

Limitations

There are several limitations which must be considered in connection to the findings of this study. Five bereaved caregivers participated in this study and although themes were identified in the data and there are similarities and parallels in some of their experiences, caregiving at end of life remains a deeply personal and unique experience which is influenced by a variety of individual factors. The findings of this study do not represent all bereaved caregivers as this study explored the experiences of five specific caregivers. The participants were all female. Three participants described their ethnic background as Caucasian, one identified as Canadian, and another identified as Ukrainian. Although this study had participants from varied ages, the participants were not from diverse gender or ethnic backgrounds.

This retrospective study focused on the first year of the COVID pandemic in Manitoba. There were several unforeseeable delays in the study from the time the thesis proposal was completed and when the study received ethics approval from the University of Manitoba and Shared Health. Recruitment did not start until September 2022 and the first interview occurred in October 2022. The final interview with the final participant occurred at the end of December 2022. Participants were reflecting retrospectively on a time that for some participants, was a period of 2 and a half years. It is unknown if the findings of the study would be different if participants were reflecting on their caregiving experience that had more recently occurred.

The delay between the proposal and ethics approval also created a challenge for recruitment as the interdisciplinary palliative care team who were asked to assist with recruitment reported it was difficult to go back into their notes and contact caregivers from nearly 2 and a half years ago. The palliative care team reported it was difficult to find participants who met criteria for the study and specifically, the criteria of providing care and/or support to a loved one at some point during March 2020-March 2021 and the loved one having had died during the period of March 2020-March 2021 made recruitment difficult and may have impacted why this study had only five participants.

Strengths

A phenomenological approach allowed for the collection of rich qualitative data which focused on lived experiences of beavered caregivers. This was the most appropriate approach for this study as caregiving at EOL is a unique and personal experience. This study aimed to learn from informal caregivers and contribute to a new area of research emerging related to COVID.

The researcher was immersed in the data and followed Braun & Clarke's (2006) step by step approach to thematic analysis. The findings represent the entire data set and the data extracts presented in the findings chapter tell the "analytic narrative" and "illustrates the story" of the data as it relates to this study's research question, aims and purpose (Braun & Clarke, 2006, p. 93).

Implications for Social Workers and Other Health Care Professionals

The findings of this study have important implications social workers and other health care professionals. This study explored the lived experiences of beavered caregivers who provided care and support to a loved one during the COVID pandemic. This study was an opportunity for social workers and other health care professionals working in palliative care to learn from bereaved caregivers. There are important implications for practice.

It has been discussed how palliative care is a holistic person-centered approach to care which focuses on enhancing quality of life. The findings have demonstrated how the pandemic impacted the caregiving and bereavement experiences of caregivers in several negative ways. If palliative care providers are to provide quality end of life care it's imperative they learn about what they can change in their practice to improve EOL care during a pandemic. It's important to recognize that social workers and other health care professionals working on the front line cannot on their own make decisions to increase staffing, resources or change policy and public health orders. There is still much within their control. Social workers and other health care professionals must use their voice, positions of power, and their expertise to advocate for change and balance.

Social workers in Manitoba are guided by the Manitoba College of Social Workers Standards of Practice for Social Workers and the Canadian Association of Social Workers Social Work Code of Ethics and Guidelines for Ethical Practice. Standard 8 in the Standards of Practice for Social Workers is the standard on advocacy and public policy and it states “social workers will use their specialized training, professional values, and experience to advocate for and to promote social justice and public policy that will serve to enhance human well-being” (Manitoba College of Social Workers, 2021, p. 16). Social workers must advocate for a balanced approach in times of a pandemic which takes into consideration the importance of safety measures and precautions with the psychosocial needs at EOL. Social workers can advocate for changes in programs and services, improvements in existing systems, and promote new models of care which are informed by patients, clients, and caregivers.

Contributions to Social Work

This study makes several contributions to social work. Prior to this study, an understanding of the lived experiences of bereaved caregivers during the COVID pandemic in a Manitoban context was missing in the literature. This study contributed rich lived experiences of the caregiver participants and this should inform palliative care social work practice. Social workers must recognize how the pandemic negatively impacted the caregiving as well as the bereavement experience. Social workers play critical roles within the health care team in addressing the psychosocial needs of caregivers. Assessment is key to addressing needs and this study suggests that the caregiving experience and bereavement experience remain unique, even during times of a pandemic. This outlines the importance for social workers to complete thorough psychosocial assessments.

This study contributed to the knowledge of end-of-life caregiver’s needs related to the

COVID pandemic. If there are future waves of COVID or another pandemic, social workers can learn from the findings of this research. Specifically, the findings regarding the isolation, delayed grief, financial impact, and overall challenges experienced by caregivers. This study has demonstrated that caregivers have had positive experiences with social workers in palliative care and a key recommendation participants had is that more bereavement support is needed. When bereavement support is provided, this study has demonstrated that caregivers prefer in person support rather than virtual.

Study Recommendations

The literature review and findings of this study have informed several recommendations for policy and the health care system, social work, and recommendations for research.

Recommendations for Policy and the Health Care System

The findings of this study illustrate the profound effects public health orders had on end-of-life caregiver's caregiving and bereavement experiences. This has important implications for government leaders who are responsible for establishing public health orders and health care leaders responsible for establishing visitation policies. The findings suggest that more flexibility in the rules or further exceptions for end-of-life situations is required if another pandemic occurs. Specifically, it is recommended that visitation in all institutional settings as well as private residences for individuals facing end of life should be considered exceptional situations and rules should be flexible and balanced. The safety of the masses remains important but if future waves of COVID or another pandemic occurs, flexibility and exceptions should be considered while maintaining safety protocols such as PPE and symptom screening. The isolation, loneliness, and lack of physical contact reported by participants resulted in increased distress for EOL caregivers and increased the risk for complicated grief.

Additionally, it is recommended that if there are future waves of COVID or another pandemic, rules that honour the need for people to grieve, to gather for celebrations and commemorate together should be considered. The findings of this study demonstrate that interrupted grief and commemoration resulted in lack of closure, delayed grief and difficult grief.

Overall, it is recommended that policies and public health orders regarding the pandemic give consideration to end of life situations with an approach that balances safety with the psychosocial and practical needs of EOL caregivers and patients. A balanced approach which embraces the holistic person-centered approach in palliative end of life care is crucial.

This study has important implications for the overall health care system. The findings revealed that consistent staff, more bereavement support, and stable, enhanced community-based staffing resources are areas identified by caregivers where improvements are needed. The Government of Canada (2021, p. 31) state:

> As the country moves through oncoming waves of this pandemic and looks towards the future, it will be important to continue to scan for new and innovative ways of delivering palliative home and community [care] in order to improve the lives of Canadians in need of palliative care and at end of life, caregivers, and staff.

It's imperative that as improvements and changes are made to end of life care, health care leaders and local, provincial, and federal policymakers engage meaningfully with patients and families. There is much more to be learned from the lived experiences of EOL caregivers and EOL patients.

Improvements are needed in the area of data. Data regarding inequities in access to palliative care is difficult to examine as the Canadian Institute for Health Information explains that “data does not include comprehensive information on some patient characteristics such as race, religion, and language" (Canadian Institute for Health Information, 2023, p. 16). Equity in access to palliative care services is an area in need of further attention and equity in health care must be considered in relation to the social determinants of health. It is recommended that data regarding the social determinants of health is collected to provide a full view of palliative care and where gaps in access to care exist.

Recommendations for Social Work

The findings of this study are important for all health care professionals and most notably, social workers, as their role in palliative care is to provide skilled psychosocial support. It has been discussed that palliative care is a holistic approach to care. It's imperative that the psycho-emotional needs of caregivers at EOL are addressed and supported by social workers.

This thesis document has reviewed the importance of screening for complicated grief, providing bereavement support, the importance of preparing caregivers emotionally for the death of their loved ones amongst other key areas integral to the role of social work. It is recommended that educational institutions delivering social work programs ensure that social workers enter practice with the entry level skills required to support caregivers within health care. It is also recommended that social workers practicing in this area engage in ongoing professional development and understand how they are obligated as a regulated profession to provide competent social work services and seek out educational and professional development opportunities to continuously improve their skill set.

The Canadian Partnership Against Cancer & Health Canada (2021) released the Canadian Interdisciplinary Palliative Care Competency Framework. Five disciplines are included in the framework including physicians, nurses, social workers, personal support workers and volunteers (Canadian Partnership Against Cancer & Health Canada, 2021). The Framework includes twelve competency domains and the nursing and social work competencies include both generalist and specialist competencies for palliative care. The Framework includes a self-assessment tool and health care providers can complete the self-assessment and identify areas of improvement. This allows health care providers including social workers to identify specific areas of professional development as it relates to palliative care competencies. The Canadian Partnership Against Cancer released a second document in 2022 titled Beginning the Journey into the Spirit World: First Nations, Inuit and Métis Approaches to Palliative and End-of-Life Care in Canada. This document "summarizes factors contributing to First Nations, Inuit and Métis palliative and end-of-life care experiences" and "identifies areas for action in palliative and end-of-life care based on priorities, gaps, challenges, and needs expressed by First Nations, Inuit and Métis Peoples and communities" (Canadian Partnership Against Cancer, 2022, p. 7). The document includes promising practices related to the twelve competency domains included in the Framework. Educational intuitions should incorporate the Framework and the document on First Nations, Inuit and Métis palliative care into electives or field focus courses for social workers interested in working in health care. It is recommended that all social workers currently working in health care review both documents and complete the social work self-assessment for palliative care competencies.

Recommendations for Future Research

Further research into specific aspects of the caregiving experience and bereavement experience as it relates to the pandemic is required. The literature review for this study revealed that the experience of caregivers whose loved ones had an assisted death during COVID has not been well researched. New research areas that require explorations includes research focusing on the experience of prolonged or complex grief related to end-of-life caregiving during the pandemic and how this relates to public health orders. In addition, research comparing specific types of terminal diseases and the impact on caregivers would benefit from further attention. Finally, another important area for future research is to explore burnout and moral distress amongst health care workers during COVID. The findings and discussion of this study suggest that it would be important to explore how pre-pandemic burnout and the effects this has on family caregivers and patients compares to post-pandemic staff burnout. It's critical to explore all of these above-mentioned areas of research within the context of Manitoba's health care system as well as overall, in a Canadian setting as pathways and access to care, resources, and overall systems differ across provinces as well as across countries.

Social Determinants of Health.

The World Health Organization (2023, para 3) outlines several social determinants of health which impact health equity:

> Income and social protection, education, unemployment and job security, working life conditions, food insecurity, housing, basic amenities and the environment, early childhood development, social inclusion and non-discrimination, structural conflict [and] access to affordable health services of decent quality.

The caregiving experience during the pandemic in the context of the social determinants of health is an important area of research where attention is required. The literature supports the notion that COVID had detrimental effects on racial minorities, individuals with lower socioeconomic status, individuals living in poverty, and women and has "exacerbated the social determinants of health" (Green et al., 2021). This topic must be further explored with EOL caregivers and particularly, with structurally vulnerable populations.

The emerging literature on the social determinants of health and the pandemic, highlights the importance of equity in a "post-COVID world" and it's explained that "understanding what a post-COVID world could look like necessitates an examination of key structural determinants that have contributed to the disproportionate effects of the COVID-19 pandemic on marginalised and other groups" (Paremoer et al., 2021, p. 1). This area of research should be explored globally. Research in this particular area could help inform where palliative care resources are needed based on an equity lens.

Conclusion

The purpose of this study was to explore the lived experiences of bereaved caregivers and this study aimed to explore their caregiving and bereavement experiences in the context of the COVID pandemic. This phenomenological qualitative study had five participants. Participants were each interviewed twice. Data was analyzed using Braun and Clarke's (2006) approach to thematic analysis. Five key themes were identified in the data: 1) impact of caregiving and the implications of public health orders, 2) interrupted grief and commemoration during a pandemic, 3) challenges with the health care system, 4) people make the difference, and 5) recommendations through reflections. This thesis document provided a detailed review of the literature, discussed the study methodology and methods, presented the findings, and discussed the findings and their implications. Then, the limitations and implications of the study were considered. Finally, contributions to social work, recommendations for policy and the health care system, recommendations for social work, and recommendations for future research were presented. It's imperative that caregivers' voices continue to be prioritized in social work and palliative care research in order to understand their lived experiences and their needs. This will support health care providers in providing a holistic approach to care at end of life.

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Appendices

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Appendix A: Research Poster

University of Manitoba | Faculty of Social Work

RESEARCH PARTICIPANTS NEEDED

BEREAVED CAREGIVERS

Are you a bereaved caregiver who provided care or support to a terminally ill individual during the first year of the COVID-19 pandemic in Manitoba?

The aim of this study is to learn about your caregiving experience and bereavement experience during the pandemic

If you agree to participate you will be asked to:

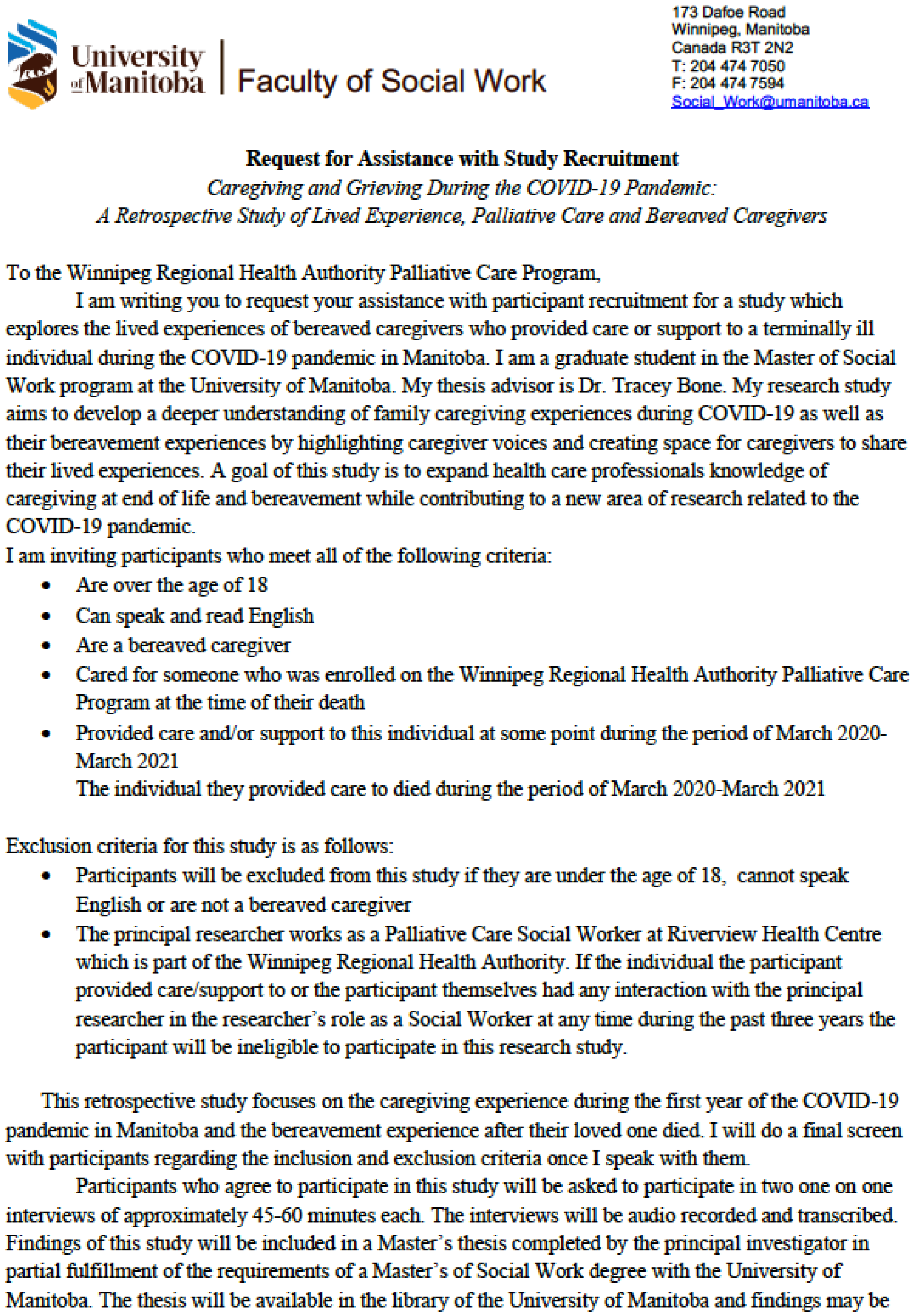
- Participate in two one on one interviews
- Share your caregiving and bereavement experience
- Your total time commitment will be approximately 2 hours
- The interviews will be over Zoom or on the phone
- This study is voluntary and in appreciation for your time and participation you will be provided a $25 gift card

For more information or to participate please contact:

Salina Fukumoto
MSW Graduate Student
[redacted]
dookhers@myumanitoba.ca
Thesis advisor: Dr. Tracey Bone
[redacted]
tracey.bone@umanitoba.ca

THIS RESEARCH HAS BEEN APPROVED BY THE RESEARCH ETHICS BOARD AT THE UNIVERSITY OF MANITOBA FORT GARRY CAMPUS.

Appendix B: Request for Assistance with Study Recruitment Letter



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Request for Assistance with Study Recruitment

Caregiving and Grieving During the COVID-19 Pandemic:
A Retrospective Study of Lived Experience, Palliative Care and Bereaved Caregivers

To the Winnipeg Regional Health Authority Palliative Care Program,

I am writing you to request your assistance with participant recruitment for a study which explores the lived experiences of bereaved caregivers who provided care or support to a terminally ill individual during the COVID-19 pandemic in Manitoba. I am a graduate student in the Master of Social Work program at the University of Manitoba. My thesis advisor is Dr. Tracey Bone. My research study aims to develop a deeper understanding of family caregiving experiences during COVID-19 as well as their bereavement experiences by highlighting caregiver voices and creating space for caregivers to share their lived experiences. A goal of this study is to expand health care professionals knowledge of caregiving at end of life and bereavement while contributing to a new area of research related to the COVID-19 pandemic.

I am inviting participants who meet all of the following criteria:

- Are over the age of 18
- Can speak and read English
- Are a bereaved caregiver
- Cared for someone who was enrolled on the Winnipeg Regional Health Authority Palliative Care Program at the time of their death
- Provided care and/or support to this individual at some point during the period of March 2020-March 2021

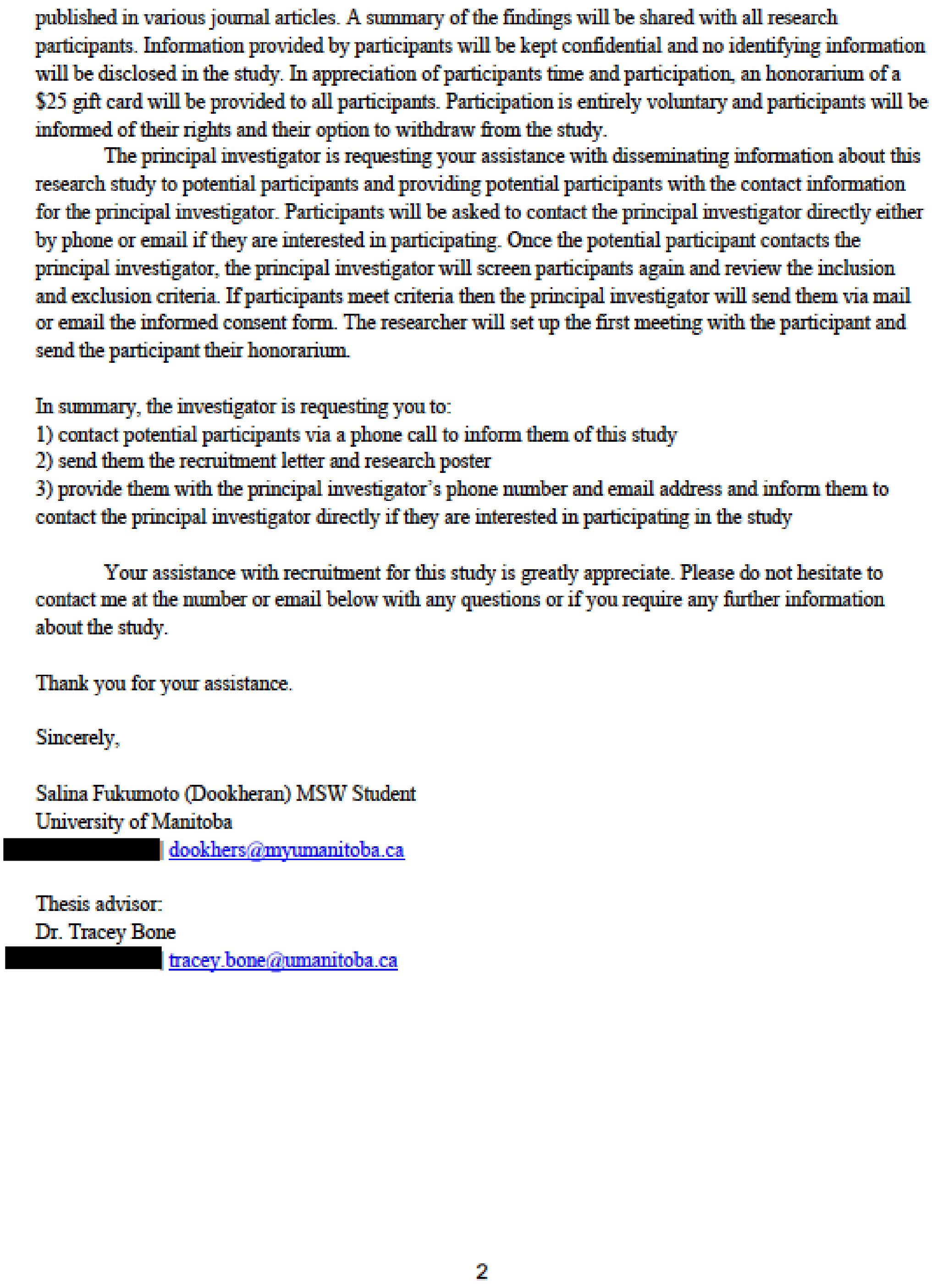
  The individual they provided care to died during the period of March 2020-March 2021

Exclusion criteria for this study is as follows:

- Participants will be excluded from this study if they are under the age of 18, cannot speak English or are not a bereaved caregiver
- The principal researcher works as a Palliative Care Social Worker at Riverview Health Centre which is part of the Winnipeg Regional Health Authority. If the individual the participant provided care/support to or the participant themselves had any interaction with the principal researcher in the researcher's role as a Social Worker at any time during the past three years the participant will be ineligible to participate in this research study.

This retrospective study focuses on the caregiving experience during the first year of the COVID-19 pandemic in Manitoba and the bereavement experience after their loved one died. I will do a final screen with participants regarding the inclusion and exclusion criteria once I speak with them.

Participants who agree to participate in this study will be asked to participate in two one on one interviews of approximately 45-60 minutes each. The interviews will be audio recorded and transcribed. Findings of this study will be included in a Master's thesis completed by the principal investigator in partial fulfillment of the requirements of a Master's of Social Work degree with the University of Manitoba. The thesis will be available in the library of the University of Manitoba and findings may be



published in various journal articles. A summary of the findings will be shared with all research participants. Information provided by participants will be kept confidential and no identifying information will be disclosed in the study. In appreciation of participants time and participation, an honorarium of a $25 gift card will be provided to all participants. Participation is entirely voluntary and participants will be informed of their rights and their option to withdraw from the study.

The principal investigator is requesting your assistance with disseminating information about this research study to potential participants and providing potential participants with the contact information for the principal investigator. Participants will be asked to contact the principal investigator directly either by phone or email if they are interested in participating. Once the potential participant contacts the principal investigator, the principal investigator will screen participants again and review the inclusion and exclusion criteria. If participants meet criteria then the principal investigator will send them via mail or email the informed consent form. The researcher will set up the first meeting with the participant and send the participant their honorarium.

In summary, the investigator is requesting you to:
1) contact potential participants via a phone call to inform them of this study
2) send them the recruitment letter and research poster
3) provide them with the principal investigator's phone number and email address and inform them to contact the principal investigator directly if they are interested in participating in the study

Your assistance with recruitment for this study is greatly appreciate. Please do not hesitate to contact me at the number or email below with any questions or if you require any further information about the study.

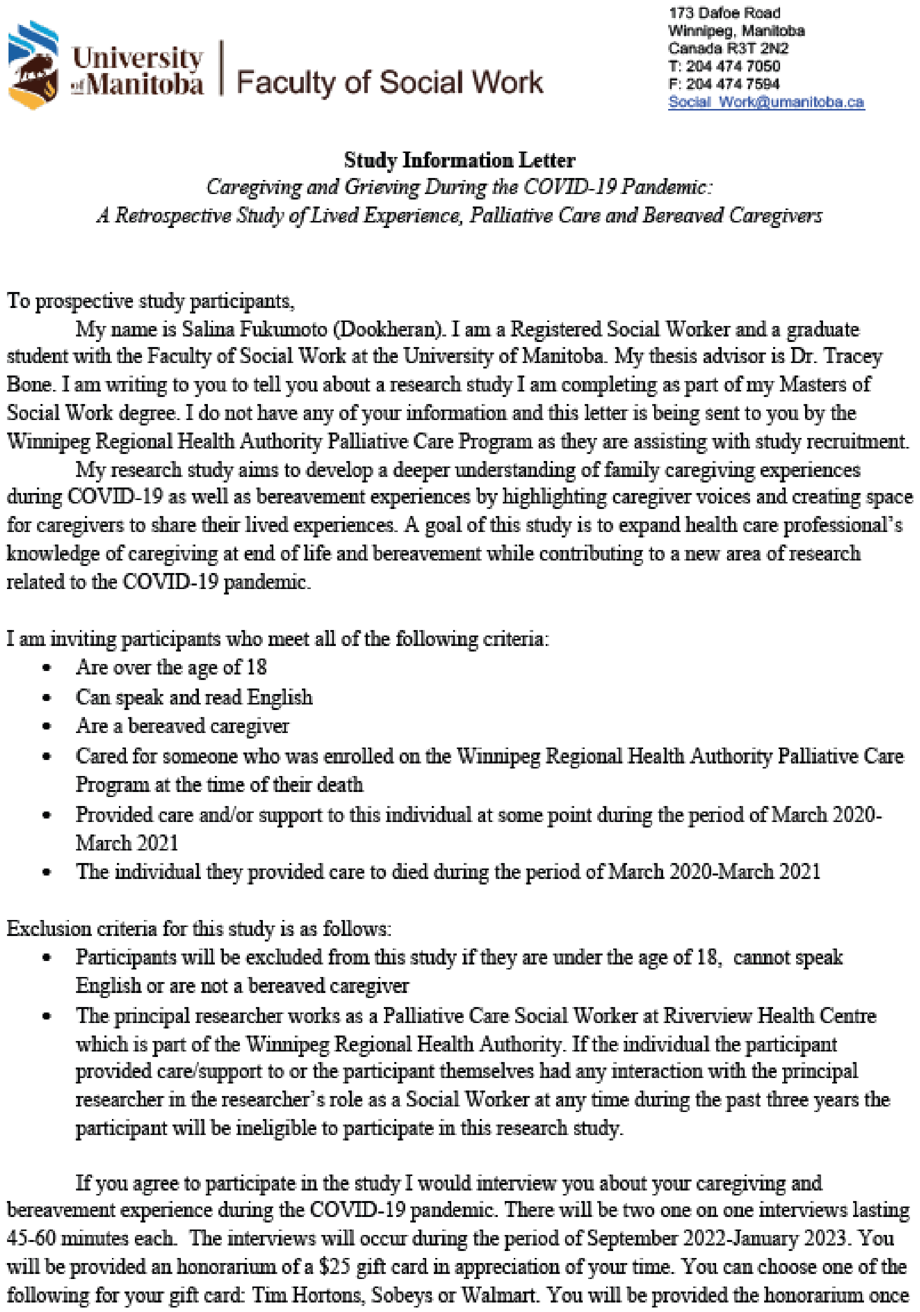
Thank you for your assistance.

Sincerely,

Salina Fukumoto (Dookheran) MSW Student
University of Manitoba
[redacted] dookhers@myumanitoba.ca

Thesis advisor:
Dr. Tracey Bone
[redacted] tracey.bone@umanitoba.ca

Appendix C: Study Information Letter



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Study Information Letter

Caregiving and Grieving During the COVID-19 Pandemic:
A Retrospective Study of Lived Experience, Palliative Care and Bereaved Caregivers

To prospective study participants,

My name is Salina Fukumoto (Dookheran). I am a Registered Social Worker and a graduate student with the Faculty of Social Work at the University of Manitoba. My thesis advisor is Dr. Tracey Bone. I am writing to you to tell you about a research study I am completing as part of my Masters of Social Work degree. I do not have any of your information and this letter is being sent to you by the Winnipeg Regional Health Authority Palliative Care Program as they are assisting with study recruitment.

My research study aims to develop a deeper understanding of family caregiving experiences during COVID-19 as well as bereavement experiences by highlighting caregiver voices and creating space for caregivers to share their lived experiences. A goal of this study is to expand health care professional's knowledge of caregiving at end of life and bereavement while contributing to a new area of research related to the COVID-19 pandemic.

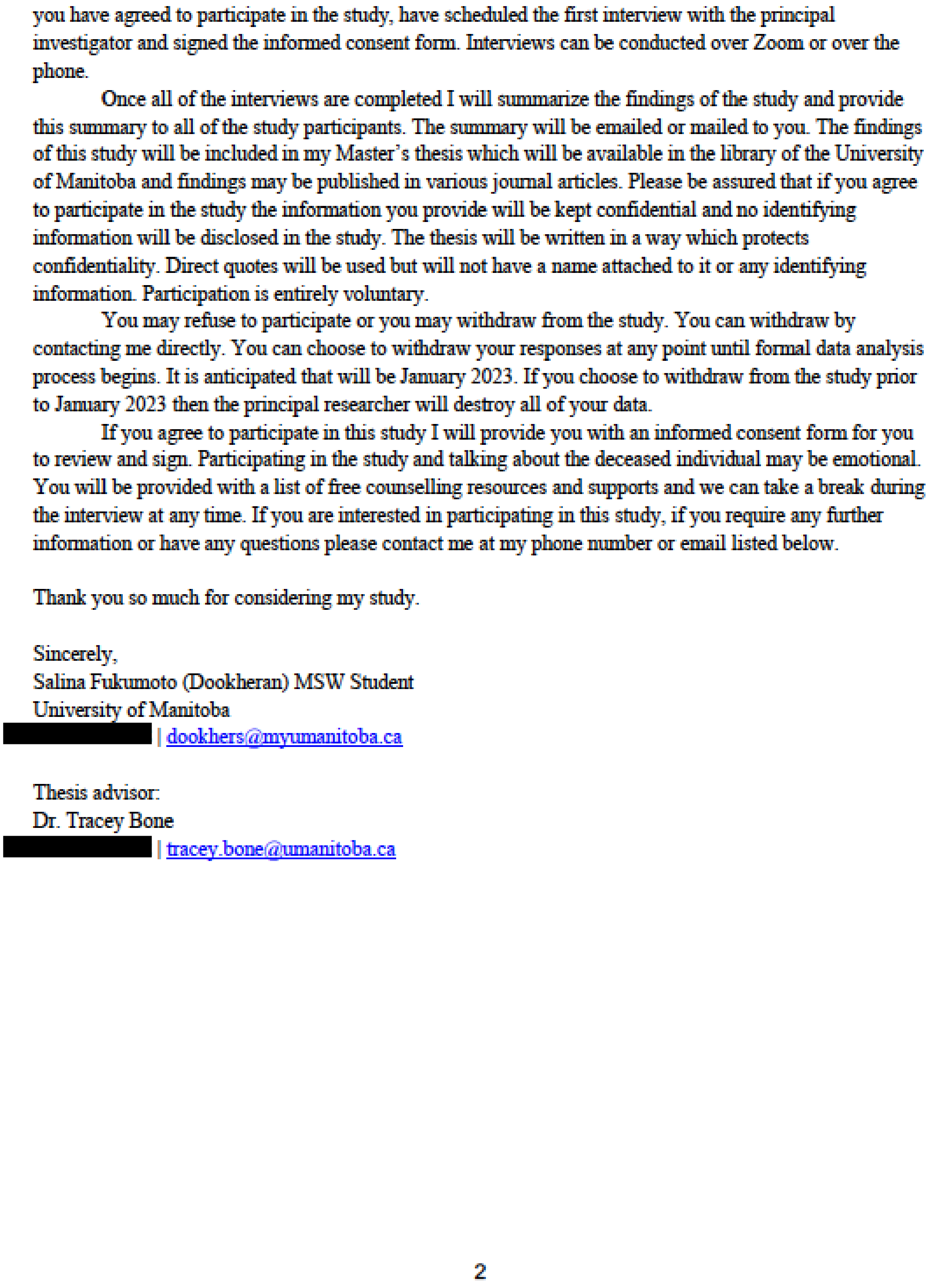
I am inviting participants who meet all of the following criteria:

- Are over the age of 18
- Can speak and read English
- Are a bereaved caregiver
- Cared for someone who was enrolled on the Winnipeg Regional Health Authority Palliative Care Program at the time of their death
- Provided care and/or support to this individual at some point during the period of March 2020-March 2021
- The individual they provided care to died during the period of March 2020-March 2021

Exclusion criteria for this study is as follows:

- Participants will be excluded from this study if they are under the age of 18, cannot speak English or are not a bereaved caregiver
- The principal researcher works as a Palliative Care Social Worker at Riverview Health Centre which is part of the Winnipeg Regional Health Authority. If the individual the participant provided care/support to or the participant themselves had any interaction with the principal researcher in the researcher's role as a Social Worker at any time during the past three years the participant will be ineligible to participate in this research study.

If you agree to participate in the study I would interview you about your caregiving and bereavement experience during the COVID-19 pandemic. There will be two one on one interviews lasting 45-60 minutes each. The interviews will occur during the period of September 2022-January 2023. You will be provided an honorarium of a $25 gift card in appreciation of your time. You can choose one of the following for your gift card: Tim Hortons, Sobeys or Walmart. You will be provided the honorarium once



you have agreed to participate in the study, have scheduled the first interview with the principal investigator and signed the informed consent form. Interviews can be conducted over Zoom or over the phone.

Once all of the interviews are completed I will summarize the findings of the study and provide this summary to all of the study participants. The summary will be emailed or mailed to you. The findings of this study will be included in my Master's thesis which will be available in the library of the University of Manitoba and findings may be published in various journal articles. Please be assured that if you agree to participate in the study the information you provide will be kept confidential and no identifying information will be disclosed in the study. The thesis will be written in a way which protects confidentiality. Direct quotes will be used but will not have a name attached to it or any identifying information. Participation is entirely voluntary.

You may refuse to participate or you may withdraw from the study. You can withdraw by contacting me directly. You can choose to withdraw your responses at any point until formal data analysis process begins. It is anticipated that will be January 2023. If you choose to withdraw from the study prior to January 2023 then the principal researcher will destroy all of your data.

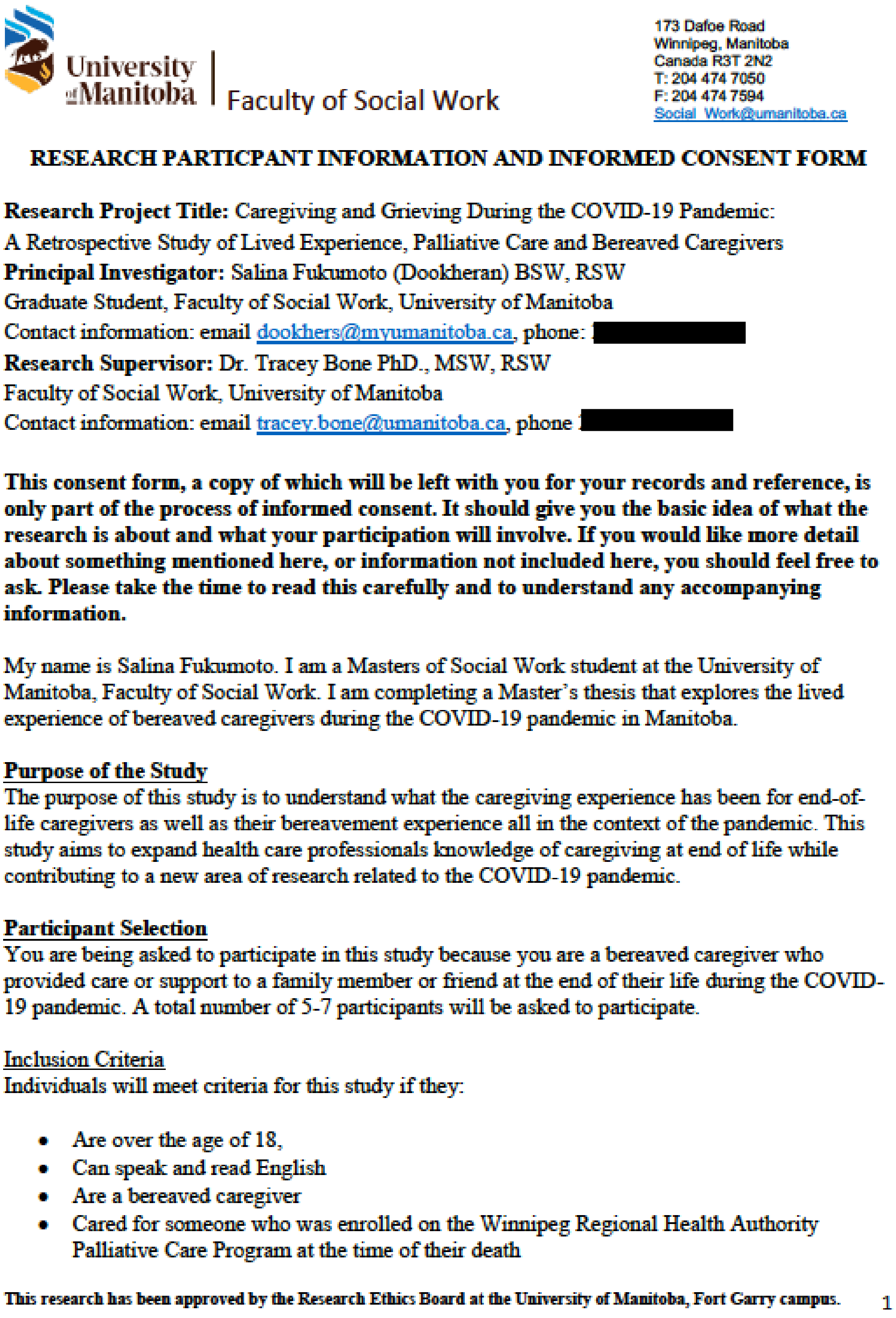
If you agree to participate in this study I will provide you with an informed consent form for you to review and sign. Participating in the study and talking about the deceased individual may be emotional. You will be provided with a list of free counselling resources and supports and we can take a break during the interview at any time. If you are interested in participating in this study, if you require any further information or have any questions please contact me at my phone number or email listed below.

Thank you so much for considering my study.

Sincerely,
Salina Fukumoto (Dookheran) MSW Student
University of Manitoba
[redacted] | dookhers@myumanitoba.ca

Thesis advisor:
Dr. Tracey Bone
[redacted] | tracey.bone@umanitoba.ca

Appendix D: Informed Consent



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RESEARCH PARTICPANT INFORMATION AND INFORMED CONSENT FORM

Research Project Title: Caregiving and Grieving During the COVID-19 Pandemic:
A Retrospective Study of Lived Experience, Palliative Care and Bereaved Caregivers
Principal Investigator: Salina Fukumoto (Dookheran) BSW, RSW
Graduate Student, Faculty of Social Work, University of Manitoba
Contact information: email dookhers@myumanitoba.ca, phone: [redacted]
Research Supervisor: Dr. Tracey Bone PhD., MSW, RSW
Faculty of Social Work, University of Manitoba
Contact information: email tracey.bone@umanitoba.ca, phone [redacted]

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

My name is Salina Fukumoto. I am a Masters of Social Work student at the University of Manitoba, Faculty of Social Work. I am completing a Master's thesis that explores the lived experience of bereaved caregivers during the COVID-19 pandemic in Manitoba.

Purpose of the Study

The purpose of this study is to understand what the caregiving experience has been for end-of-life caregivers as well as their bereavement experience all in the context of the pandemic. This study aims to expand health care professionals knowledge of caregiving at end of life while contributing to a new area of research related to the COVID-19 pandemic.

Participant Selection

You are being asked to participate in this study because you are a bereaved caregiver who provided care or support to a family member or friend at the end of their life during the COVID-19 pandemic. A total number of 5-7 participants will be asked to participate.

Inclusion Criteria

Individuals will meet criteria for this study if they:

- Are over the age of 18,
- Can speak and read English
- Are a bereaved caregiver
- Cared for someone who was enrolled on the Winnipeg Regional Health Authority Palliative Care Program at the time of their death

This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus.

- Provided care and/or support to this individual at some point during the period of March 2020-March 2021
- The individual they provided care to died during the period of March 2020-March 2021

Exclusion Criteria

- Participants will be excluded from this study if they are under the age of 18, cannot speak English or are not a bereaved caregiver
- The principal researcher works as a Palliative Care Social Worker at Riverview Health Centre which is part of the Winnipeg Regional Health Authority. If the individual the participant provided care/support to or the participant themselves had any interaction with the principal researcher in the researcher's role as a Social Worker at any time during the past two years the participant will be ineligible to participate in this research study.

Description of Research Procedures:

If you consent to participating in this research study you will be asked to:

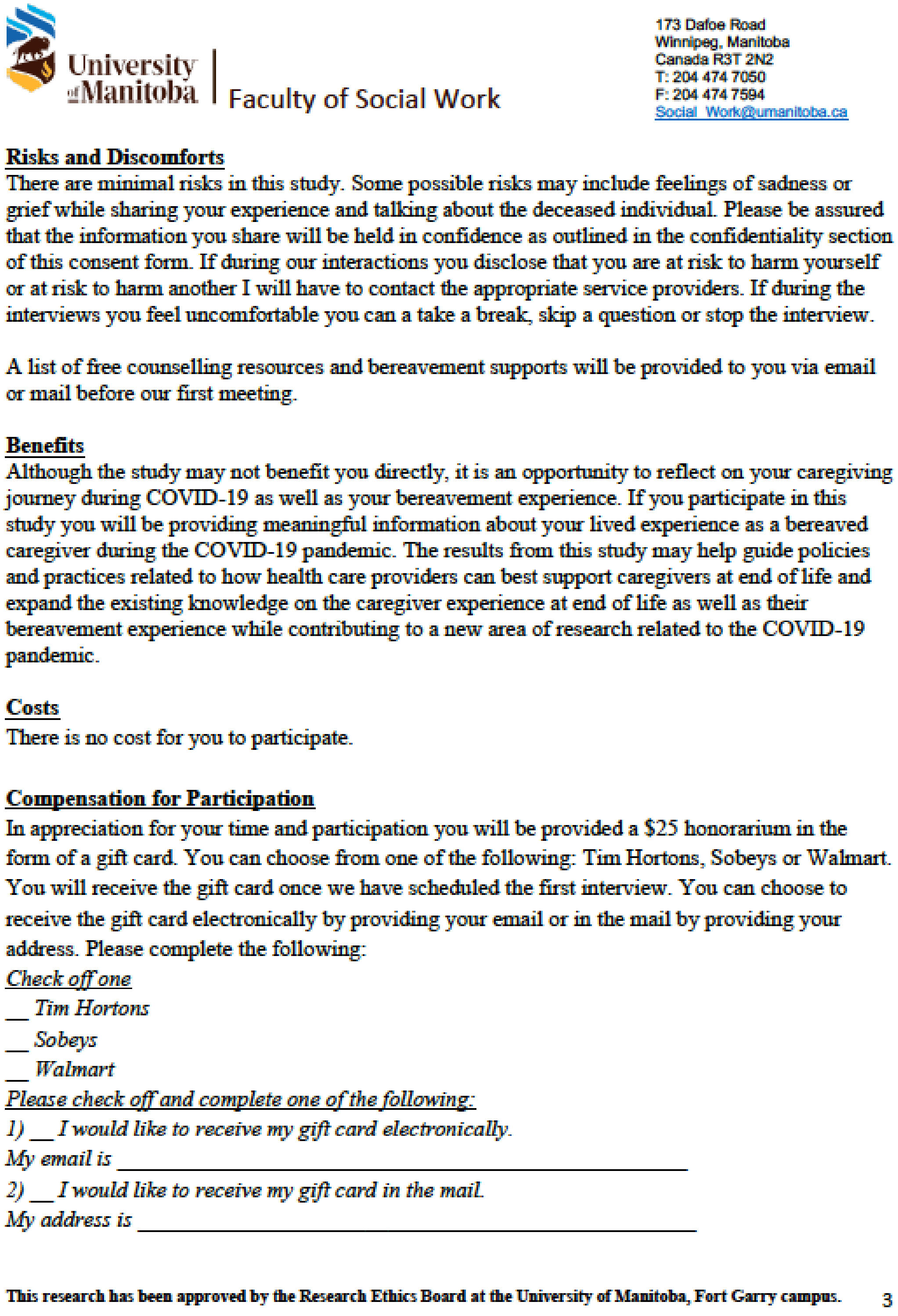
1. Sign this informed consent form
2. Complete a demographic form during the first interview with the researcher which asks you to answer 10 short questions about your age, relationship to the deceased individual, the terminal illness of the deceased individual, the date when they died, the location of their death, your employment status, level of education, your ethnic background, the type of caregiving responsibilities you had (physical, emotional and/or financial) and on average the number of hours per week you provided care.
3. Participate in two one-on-one interviews of approximately 45-60 minutes each where we will talk about your experience as a caregiver at end of life and your bereavement experience during COVID-19. The interviews will be conducted over Zoom or over the phone. Pending any unforeseen circumstances, the second meeting will take place approximately 2-3 weeks after the first meeting. The interviews will take place approximately during the period of September 2022-January 2023. Overall, participants will be asked to dedicate approximately 2 hours of their time (two meetings of 1 hour each) over a period of approximately one month. The participant will only be asked to meet twice.

Audio Recording and Transcription

The interviews will be audio recorded using an audio recorder and transcribed manually by the myself, the principal researcher. Notes will also be taken by myself during the interview in a research journal.

Please check and initial:

_______ I consent to audio recording



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Risks and Discomforts

There are minimal risks in this study. Some possible risks may include feelings of sadness or grief while sharing your experience and talking about the deceased individual. Please be assured that the information you share will be held in confidence as outlined in the confidentiality section of this consent form. If during our interactions you disclose that you are at risk to harm yourself or at risk to harm another I will have to contact the appropriate service providers. If during the interviews you feel uncomfortable you can a take a break, skip a question or stop the interview.

A list of free counselling resources and bereavement supports will be provided to you via email or mail before our first meeting.

Benefits

Although the study may not benefit you directly, it is an opportunity to reflect on your caregiving journey during COVID-19 as well as your bereavement experience. If you participate in this study you will be providing meaningful information about your lived experience as a bereaved caregiver during the COVID-19 pandemic. The results from this study may help guide policies and practices related to how health care providers can best support caregivers at end of life and expand the existing knowledge on the caregiver experience at end of life as well as their bereavement experience while contributing to a new area of research related to the COVID-19 pandemic.

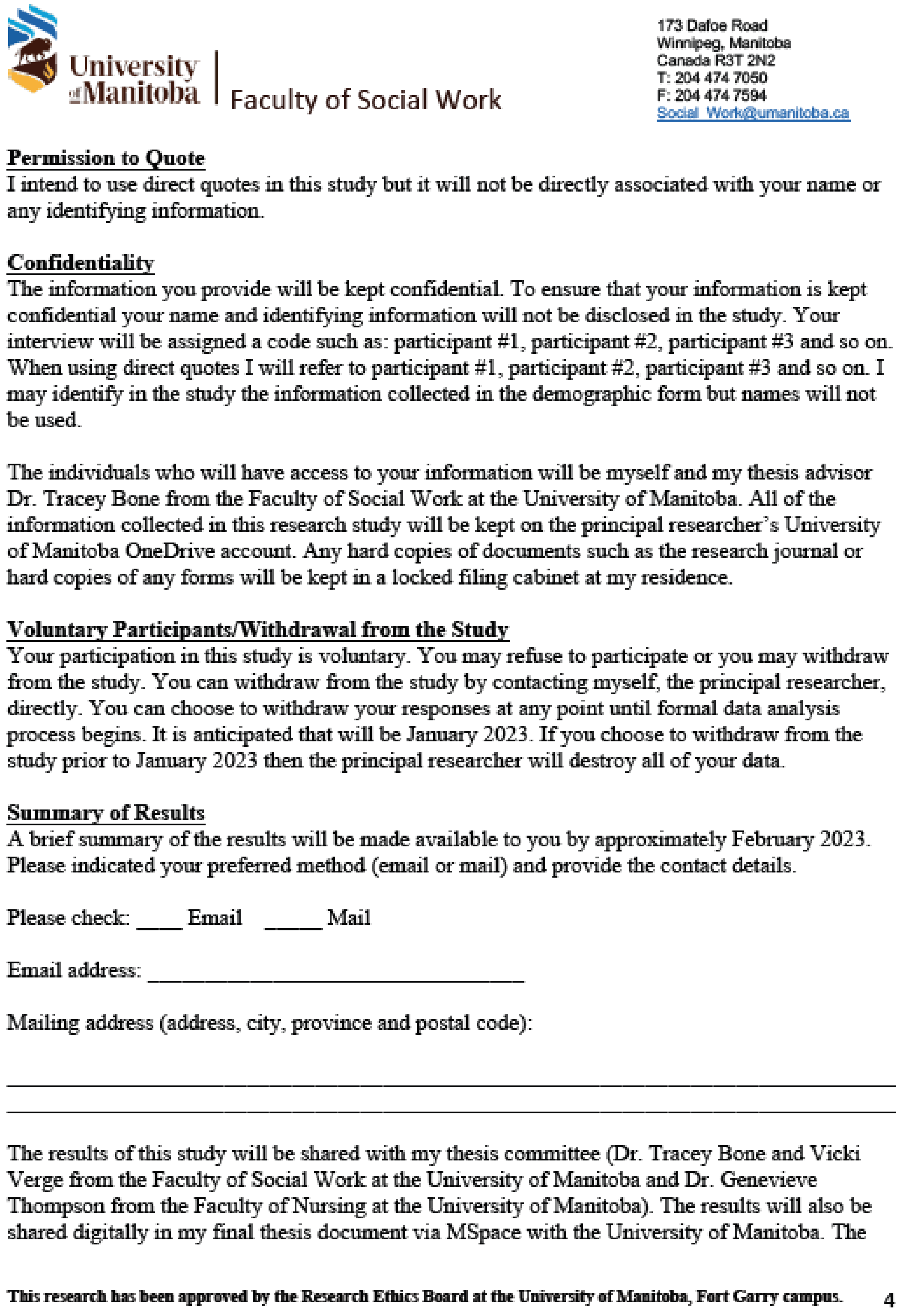
Costs

There is no cost for you to participate.

Compensation for Participation

In appreciation for your time and participation you will be provided a $25 honorarium in the form of a gift card. You can choose from one of the following: Tim Hortons, Sobeys or Walmart. You will receive the gift card once we have scheduled the first interview. You can choose to receive the gift card electronically by providing your email or in the mail by providing your address. Please complete the following:

Check off one
__ *Tim Hortons*
__ *Sobeys*
__ *Walmart*
Please check off and complete one of the following:
1) __ I would like to receive my gift card electronically.
My email is ____
2) __ I would like to receive my gift card in the mail.
My address is ____



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Permission to Quote
I intend to use direct quotes in this study but it will not be directly associated with your name or any identifying information.

Confidentiality
The information you provide will be kept confidential. To ensure that your information is kept confidential your name and identifying information will not be disclosed in the study. Your interview will be assigned a code such as: participant #1, participant #2, participant #3 and so on. When using direct quotes I will refer to participant #1, participant #2, participant #3 and so on. I may identify in the study the information collected in the demographic form but names will not be used.

The individuals who will have access to your information will be myself and my thesis advisor Dr. Tracey Bone from the Faculty of Social Work at the University of Manitoba. All of the information collected in this research study will be kept on the principal researcher's University of Manitoba OneDrive account. Any hard copies of documents such as the research journal or hard copies of any forms will be kept in a locked filing cabinet at my residence.

Voluntary Participants/Withdrawal from the Study
Your participation in this study is voluntary. You may refuse to participate or you may withdraw from the study. You can withdraw from the study by contacting myself, the principal researcher, directly. You can choose to withdraw your responses at any point until formal data analysis process begins. It is anticipated that will be January 2023. If you choose to withdraw from the study prior to January 2023 then the principal researcher will destroy all of your data.

Summary of Results
A brief summary of the results will be made available to you by approximately February 2023. Please indicated your preferred method (email or mail) and provide the contact details.

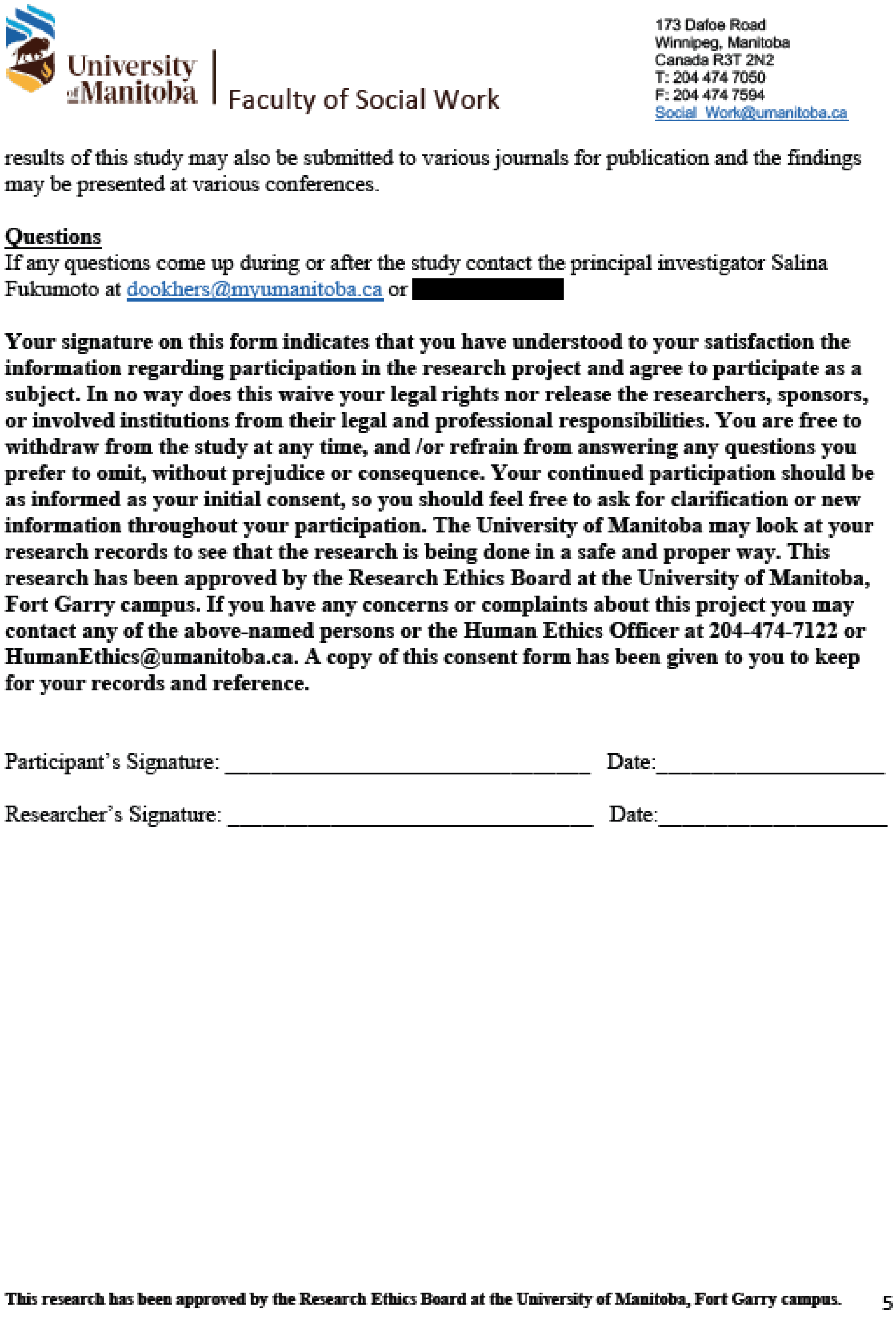
Please check: ____ Email _____ Mail

Email address: ___________________________________

Mailing address (address, city, province and postal code):

____
____

The results of this study will be shared with my thesis committee (Dr. Tracey Bone and Vicki Verge from the Faculty of Social Work at the University of Manitoba and Dr. Genevieve Thompson from the Faculty of Nursing at the University of Manitoba). The results will also be shared digitally in my final thesis document via MSpace with the University of Manitoba. The



results of this study may also be submitted to various journals for publication and the findings may be presented at various conferences.

Questions

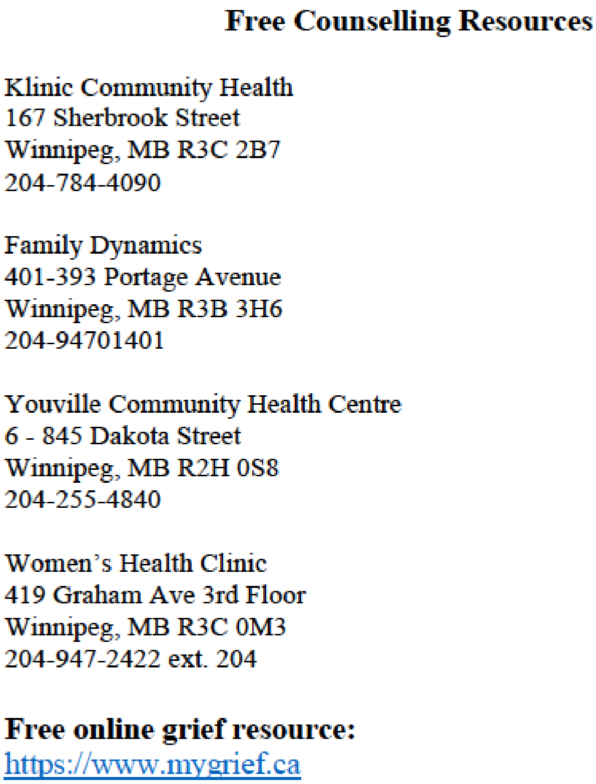
If any questions come up during or after the study contact the principal investigator Salina Fukumoto at dookhers@myumanitoba.ca or [redacted]

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Officer at 204-474-7122 or HumanEthics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature: ________________________________ Date:____________________

Researcher's Signature: ________________________________ Date:____________________

Appendix E: List of Counselling Resources



Free Counselling Resources

Klinic Community Health
167 Sherbrook Street
Winnipeg, MB R3C 2B7
204-784-4090

Family Dynamics
401-393 Portage Avenue
Winnipeg, MB R3B 3H6
204-94701401

Youville Community Health Centre
6 - 845 Dakota Street
Winnipeg, MB R2H 0S8
204-255-4840

Women's Health Clinic
419 Graham Ave 3rd Floor
Winnipeg, MB R3C 0M3
204-947-2422 ext. 204

Free online grief resource:
https://www.mygrief.ca

Appendix F: Interview Questions

Interview Questions

Thank you for agreeing to take the time to meet with me and for participating in this research study. As indicated on the consent form, the purpose of this study is to explore the lived experience of bereaved caregivers who provided end of life care or support to a terminally ill family member or friend during the COVID-19 global pandemic. Specifically, this study focuses on your caregiving experience during the first year of COVID-19 in Manitoba (March 2020-March 2021) and this study also explores your bereavement experience during the entirety pandemic.

1) Tell me about your experience as a caregiver at EOL during the pandemic

   Can you share any specific moments or experiences?

2) Tell me about your bereavement experience during the pandemic. Did the pandemic impact your bereavement experience and if so, how?

   Can you share any specific moments or experiences?

   How did it feel to grieve during a pandemic?

3) Did the pandemic impact you as a caregiver financially, physically or emotionally, and if so, how?

   Can you provide any specific examples?

4) Tell me about your experience with the palliative care team

   For example, the palliative care nurses, physicians, social workers

5) Tell me about what supports you were provided by the palliative care team

   Can you provide any examples of the support you received or suggestions for support you would have found helpful?

6) Do you have any recommendations on how the palliative care team can better support caregivers at EOL during the pandemic

   Are there any specific suggestions you have for the team during the caregiving experience as well as during the grief experience?

7) Is there anything else would you like to share about your caregiving or bereavement experience

Appendix G: Demographic Form

Demographic Form

What is your age? _________ (fill in the number)

What is your relationship to the individual you provided care to? ________________________

What was the individual's terminal illness? _________________________________

When did the individual die? ___________________________ (fill in the date)

Where did the individual die? Please circle: home – hospital – palliative care unit – hospice

Are you employed? Please circle: YES – NO

What is your highest level of education your completed? ______________________

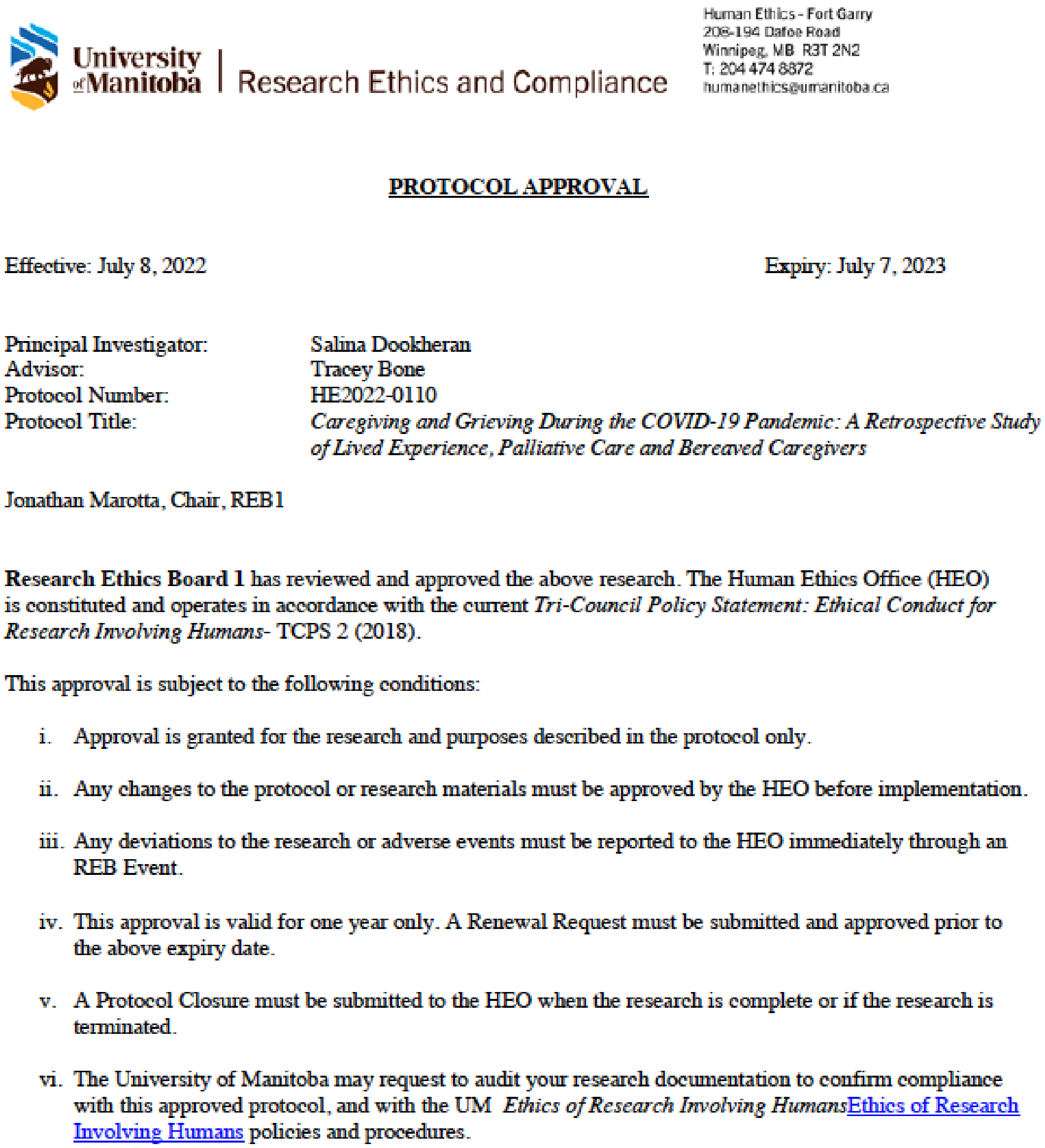
What is your ethnic background? ___________________________

What type of caregiving responsibilities did you have? (i.e.: physical care, emotional care/support, financial support)

____

On average, how many hours a week did you provide care? (fill in a number) _______________

Appendix H: University of Manitoba Research Ethics Board Approval



University of Manitoba | Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
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T: 204 474 8872
humanethics@umanitoba.ca

PROTOCOL APPROVAL

Effective: July 8, 2022 Expiry: July 7, 2023

Principal Investigator:	Salina Dookheran
Advisor:	Tracey Bone
Protocol Number:	HE2022-0110
Protocol Title:	*Caregiving and Grieving During the COVID-19 Pandemic: A Retrospective Study of Lived Experience, Palliative Care and Bereaved Caregivers*

Jonathan Marotta, Chair, REB1

Research Ethics Board 1 has reviewed and approved the above research. The Human Ethics Office (HEO) is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*- TCPS 2 (2018).

This approval is subject to the following conditions:

i. Approval is granted for the research and purposes described in the protocol only.

ii. Any changes to the protocol or research materials must be approved by the HEO before implementation.

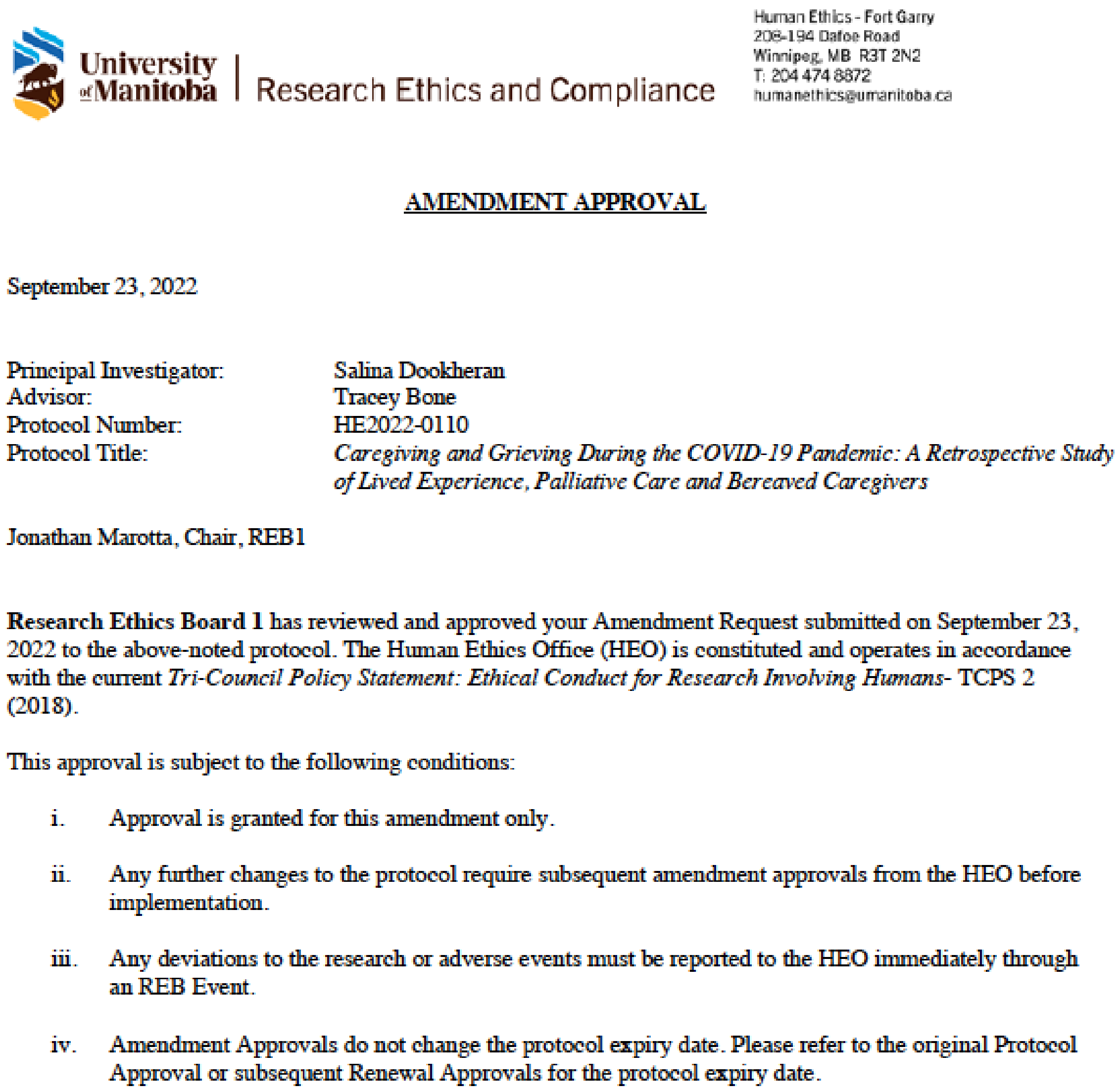
iii. Any deviations to the research or adverse events must be reported to the HEO immediately through an REB Event.

iv. This approval is valid for one year only. A Renewal Request must be submitted and approved prior to the above expiry date.

v. A Protocol Closure must be submitted to the HEO when the research is complete or if the research is terminated.

vi. The University of Manitoba may request to audit your research documentation to confirm compliance with this approved protocol, and with the UM *Ethics of Research Involving Humans*Ethics of Research Involving Humans policies and procedures.

Appendix I: University of Manitoba Research Ethics Board Amendment Approval



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AMENDMENT APPROVAL

September 23, 2022

Principal Investigator:	Salina Dookheran
Advisor:	Tracey Bone
Protocol Number:	HE2022-0110
Protocol Title:	*Caregiving and Grieving During the COVID-19 Pandemic: A Retrospective Study of Lived Experience, Palliative Care and Bereaved Caregivers*

Jonathan Marotta, Chair, REB1

Research Ethics Board 1 has reviewed and approved your Amendment Request submitted on September 23, 2022 to the above-noted protocol. The Human Ethics Office (HEO) is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*- TCPS 2 (2018).

This approval is subject to the following conditions:

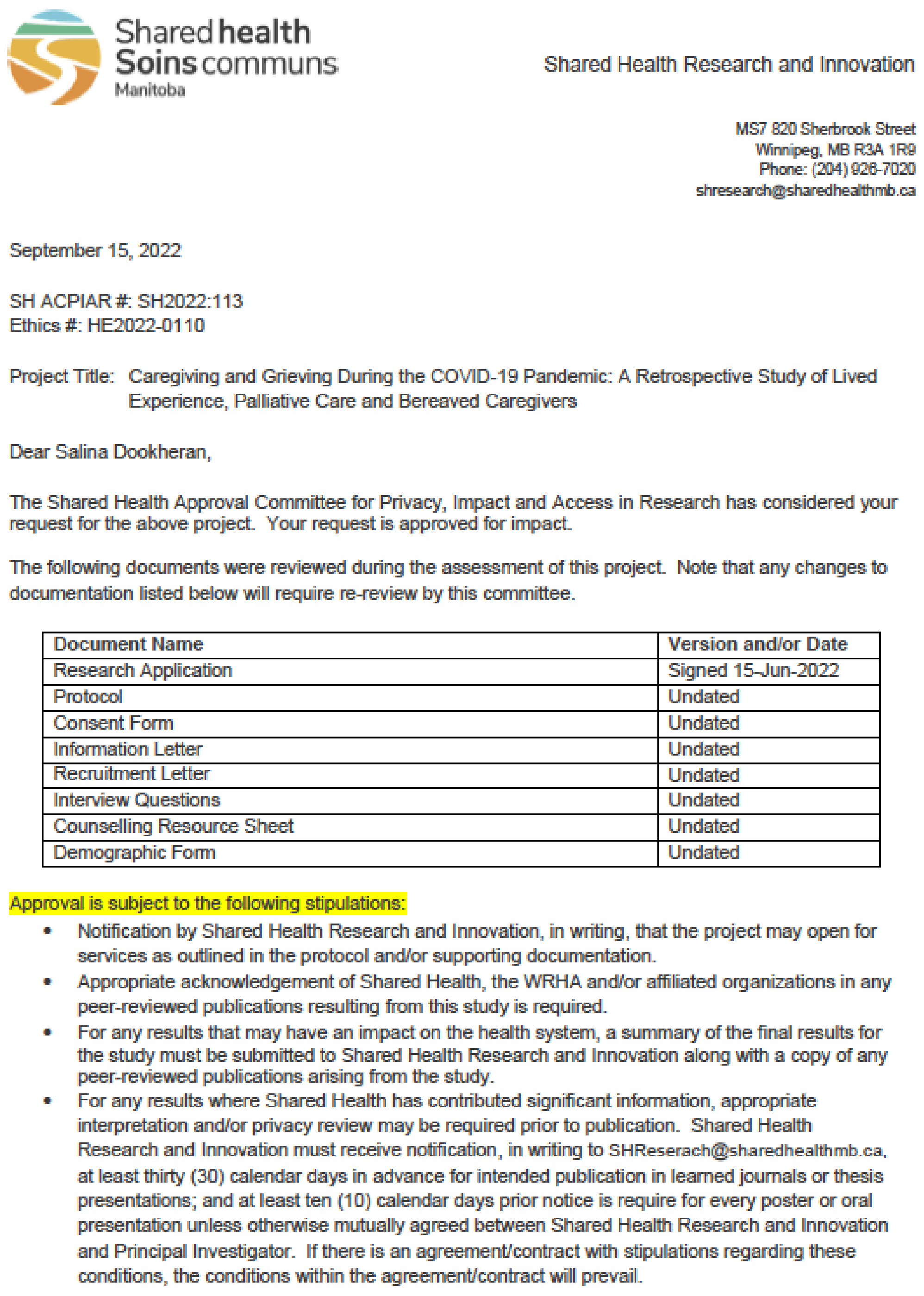
i. Approval is granted for this amendment only.

ii. Any further changes to the protocol require subsequent amendment approvals from the HEO before implementation.

iii. Any deviations to the research or adverse events must be reported to the HEO immediately through an REB Event.

iv. Amendment Approvals do not change the protocol expiry date. Please refer to the original Protocol Approval or subsequent Renewal Approvals for the protocol expiry date.

Appendix J: Shared Health Approval Committee for Privacy, Impact and Access in Research



Shared health
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Shared Health Research and Innovation

MS7 820 Sherbrook Street
Winnipeg, MB R3A 1R9
Phone: (204) 926-7020
shresearch@sharedhealthmb.ca

September 15, 2022

SH ACPIAR #: SH2022:113
Ethics #: HE2022-0110

Project Title: Caregiving and Grieving During the COVID-19 Pandemic: A Retrospective Study of Lived Experience, Palliative Care and Bereaved Caregivers

Dear Salina Dookheran,

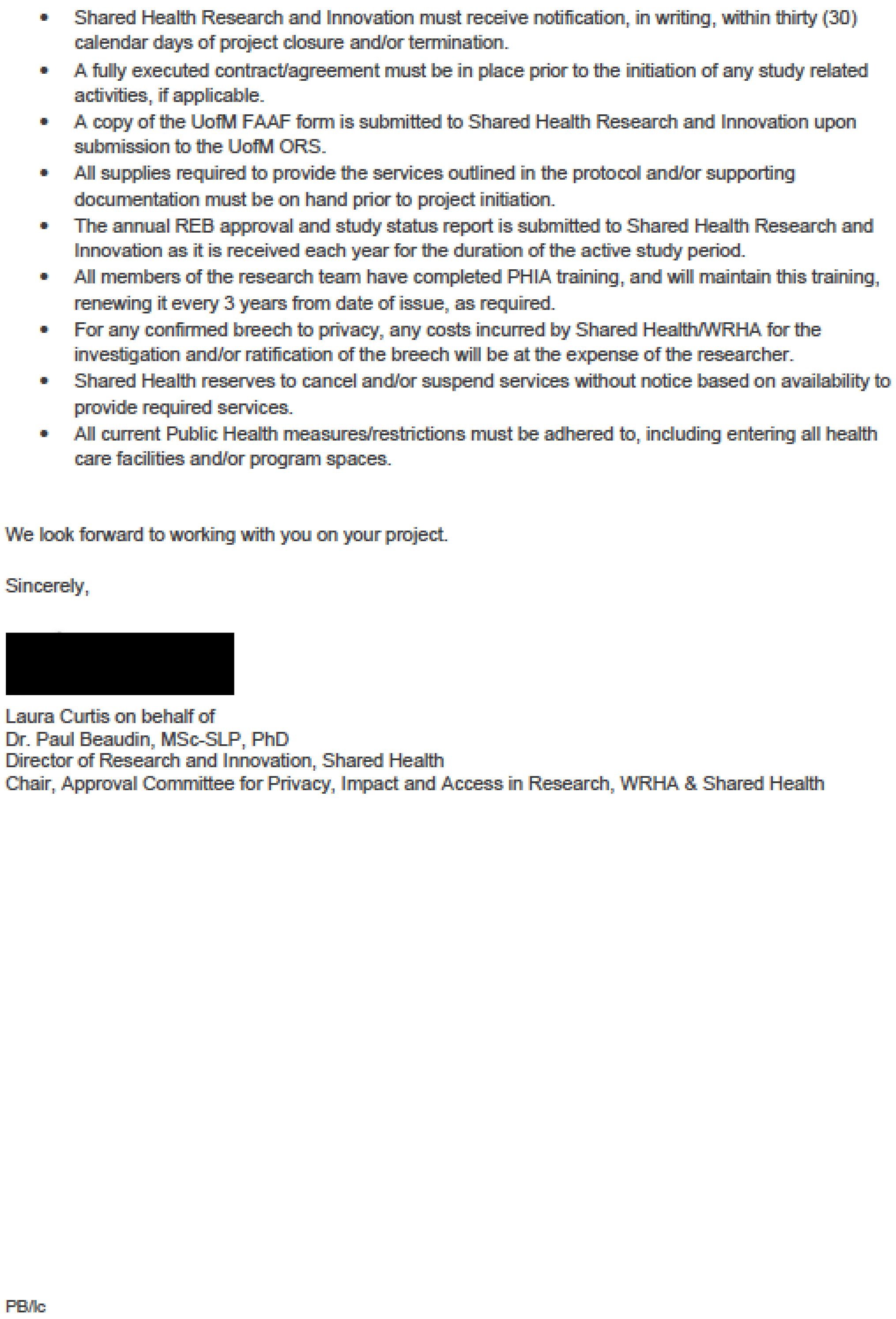
The Shared Health Approval Committee for Privacy, Impact and Access in Research has considered your request for the above project. Your request is approved for impact.

The following documents were reviewed during the assessment of this project. Note that any changes to documentation listed below will require re-review by this committee.

Document Name	**Version and/or Date**
Research Application	Signed 15-Jun-2022
Protocol	Undated
Consent Form	Undated
Information Letter	Undated
Recruitment Letter	Undated
Interview Questions	Undated
Counselling Resource Sheet	Undated
Demographic Form	Undated

Approval is subject to the following stipulations:

- Notification by Shared Health Research and Innovation, in writing, that the project may open for services as outlined in the protocol and/or supporting documentation.
- Appropriate acknowledgement of Shared Health, the WRHA and/or affiliated organizations in any peer-reviewed publications resulting from this study is required.
- For any results that may have an impact on the health system, a summary of the final results for the study must be submitted to Shared Health Research and Innovation along with a copy of any peer-reviewed publications arising from the study.
- For any results where Shared Health has contributed significant information, appropriate interpretation and/or privacy review may be required prior to publication. Shared Health Research and Innovation must receive notification, in writing to SHReserach@sharedhealthmb.ca, at least thirty (30) calendar days in advance for intended publication in learned journals or thesis presentations; and at least ten (10) calendar days prior notice is require for every poster or oral presentation unless otherwise mutually agreed between Shared Health Research and Innovation and Principal Investigator. If there is an agreement/contract with stipulations regarding these conditions, the conditions within the agreement/contract will prevail.



- Shared Health Research and Innovation must receive notification, in writing, within thirty (30) calendar days of project closure and/or termination.
- A fully executed contract/agreement must be in place prior to the initiation of any study related activities, if applicable.
- A copy of the UofM FAAF form is submitted to Shared Health Research and Innovation upon submission to the UofM ORS.
- All supplies required to provide the services outlined in the protocol and/or supporting documentation must be on hand prior to project initiation.
- The annual REB approval and study status report is submitted to Shared Health Research and Innovation as it is received each year for the duration of the active study period.
- All members of the research team have completed PHIA training, and will maintain this training, renewing it every 3 years from date of issue, as required.
- For any confirmed breech to privacy, any costs incurred by Shared Health/WRHA for the investigation and/or ratification of the breech will be at the expense of the researcher.
- Shared Health reserves to cancel and/or suspend services without notice based on availability to provide required services.
- All current Public Health measures/restrictions must be adhered to, including entering all health care facilities and/or program spaces.

We look forward to working with you on your project.

Sincerely,

[redacted]

Laura Curtis on behalf of
Dr. Paul Beaudin, MSc-SLP, PhD
Director of Research and Innovation, Shared Health
Chair, Approval Committee for Privacy, Impact and Access in Research, WRHA & Shared Health

PB/lc