Voices unheard: End-of-life experiences of Québec's English-speaking informal caregivers

Justine G. Albert

Department of Experimental Medicine

McGill University, Montreal

December 2023

A thesis submitted to McGill University in partial fulfillment of the requirements of the Master of Science degree in Experimental Medicine

Contents

List of Tables

Abstract (English)

Informal caregivers (e.g., a spouse, adult child, or friend) are pivotal in assisting individuals who face health challenges including end-of-life (EOL) decisions and care. Effective communication among all involved is essential for optimal EOL-related care processes and outcomes. In Québec, English-speaking patients, and caregivers, being a linguistic minority, can encounter unique challenges due to possible language barriers . Caregiver EOL experiences in this context require further exploration.

This qualitative study begins to explore EOL experiences among informal caregivers (N = 16) of a language minority group (English) in Québec, Canada where the majority is French speaking. Informal caregivers were conveniently recruited from the Community Health and Social Services Network (CHSSN), Senior wellness centers in various regions around Québec, and Hope & Cope – a volunteer community organization. Inclusion criteria were being at least 18 years old, having access to a phone or computer with Zoom capabilities, self-identifying as English-speaker and being a primary caregiver for someone who died by either MAiD, PSUD, or natural death within the past 5 years. Individual semi-structured (virtual) interviews were conducted with participants and lasted between 60 and 90 minutes. These were transcribed verbatim, and narratives were examined using interpretive description. Findings were structured using the Comprehensive Cancer Experience Measurement Framework, covering four domains. (1) *Individual (internal) caregiver* experiences: Overall, participants reported needing detailed information about EOL care and facing internal challenges such role conflict, feelings of guilt, and diverse opinions towards EOL decisions. (2) *Caregiver-patient shared* experiences: Participants emphasized how important shared decision-making was regarding care and death location and the patient's dependence on the caregiver. (3) *Caregiver-family shared* experiences: Participants highlighted degrees of family involvement in EOL decisions and support needed from family

members other than the primary caregiver, especially while providing care at home. (4) *Caregiver-health care system* interactions: The fourth domain was the most salient, namely how goal-concordant care (i.e., aligning professional care with patients/caregivers' goals, beliefs, and values) was construed as key in optimizing the EOL experience and its outcomes. Language barriers further challenged coming to terms with goal-concordant care. Taken together, these findings provide a deeper understanding of participants' experiences caring for someone through the EOL process and beyond.

Abstract (French)

Les aidants informels ou naturels,(à savoir un conjoint, enfant adulte ou ami) jouent un rôle essentiel dans l'aide aux personnes confrontées à des problèmes de santé, incluant la prise de décisions et les soins de fin de vie (FDV). La qualité des soins en FDV repose sur une communication efficace entre les différentes parties concernées. Au Québec, où la population anglophone constitue une minorité linguistique au sein d'un environnement majoritairement francophone, les patients et leurs soignants peuvent être confrontés à des difficultés spécifiques, exacerbées par d'éventuelles barrières linguistiques.Les expériences des aidants sont un domaine qui nécessite une exploration plus approfondie dans le contexte de FDV.

Cette étude qualitative consiste à explorer les expériences de FDV chez des aidants informels (N = 16) issus de la minorité linguistique anglophone du Québec au Canada. Nous avons recrutés des aidants informels auprès du Réseau communautaire de santé et de services sociaux (CHSSN), des centres de mieux-être pour personnes âgées de diverses régions du Québec, ainsi que par “Hope and Cope”, un organisme communautaire comprenant un groupe important de bénévoles. Les critères d'inclusion pour participer à l’étude incluaient être agé d’au moins 18 ans, avoir accès à un téléphone intelligent ou à un ordinateur permettant les communications via Zoom, s'identifier comme anglophone et d’avoir été le principal aidants d'une personne décédée que ce soit par l'aide médicale à mourir, la sédation palliative ou de façon naturelle, dans les cinq dernières années. Des entretiens individuels semi-structurés ont été conduits à distance, pour une durée de 60 à 90 minutes chacun. Ceux-ci ont été transcrits textuellement et les récits ont été examinés à l’aide d’une description interprétative. Les résultats ont été structurés autour du “Comprehensive Cancer Experience Framework”, couvrant quatre domaines. (1) Expériences individuelles (internes) des soignants: Les participants ont révélé un besoin accru d'informations détaillées sur les soins

en FDV et ont mis en évidence des défis tels que les conflits de rôles,les sentiments de culpabilité et les divergences d'opinions concernant ces décisions. (2) Expériences partagées soignant-patient: Les participants ont souligné l'importance de la prise de décision partagée concernant les soins et le lieu du décès, ainsi que la dépendance du patient à l'égard du soignant informel. (3) Expériences partagées entre le soignant et la famille: Les participants ont souligné le degré d'implication de la famille dans les décisions relatives à la FDV et le soutien indispensable des membres de la famille autres que le aidants principal, en particulier pour fournir des soins à domicile. (4) Interactions entre les soignants et le système de soins: Ce quatrième domaine s'est révélé prépondérant, illustrant comment les soins alignés sur les objectifs visés (c'est-à-dire, l'alignement des soins sur les objectifs et les valeurs des patients et des soignants) sont essentiels pour l'optimisation des processus de FDV et de leurs résultats. De plus, les barrières linguistiques ont rendu difficile certains processus de soins en termes de concordance avec les objectifs de FDV des patients et des proches. Considérés globalement, ces résultats contribuent à approfondir notre compréhension des expériences vécues par les participants en matière de soins de FDV, durant et après les étapes impliquées.

When Great Trees Fall

By Maya Angelou

When great trees fall,
rocks on distant hills shudder,
lions hunker down
in tall grasses,
and even elephants
lumber after safety.

When great trees fall
in forests,
small things recoil into silence,
their senses
eroded beyond fear.

When great souls die,
the air around us becomes
light, rare, sterile.
We breathe, briefly.
Our eyes, briefly,
see with
a hurtful clarity.
Our memory, suddenly sharpened,
examines,
gnaws on kind words
unsaid,
promised walks
never taken.

Great souls die and
our reality, bound to
them, takes leave of us.
Our souls,
dependent upon their
nurture,
now shrink, wizened.
Our minds, formed
and informed by their
radiance,
fall away.
We are not so much maddened
as reduced to the unutterable ignorance
of dark, cold
caves.

And when great souls die,
after a period peace blooms,
slowly and always
irregularly. Spaces fill
with a kind of
soothing electric vibration.
Our senses, restored, never
to be the same, whisper to us.
They existed. They existed.
We can be. Be and be
better. For they existed.

“How people die remains in the memory of those who live on.”

- Cicely Saunders

This thesis is dedicated to “those who live on” (the caregivers) – the unsung heroes who selflessly support and care for the sick and dying, embodying the resilience and compassion upon which our society relies.

Preface

This thesis represents a culmination of work and learning experience that has taken place over 27 months at McGill University in Montréal, Québec. The idea for this research project was a collaborative effort between the author (MSc candidate), the principal investigator (Dr. Carmen G. Loiselle), and Dr. Tyler Brown. Participants were recruited through various organizations around Québec including the Community Health and Social Services Network (CHSSN), 4Korners, Hope and Cope, Megantic English-speaking Community Development Corporation (MCDC), Assistance and Referral Centre (ARC), and Vision Gaspé-Percé Now. This work was funded by the Rossy Cancer Network's Kuok Fellowship for both MSc Year 1 and 2.

Acknowledgements

It is with great pleasure that I acknowledge the support and assistance of many individuals, without whom this thesis would not have been possible. I would like to express my sincere gratitude to my supervisor, Dr. Carmen G. Loiselle, for her invaluable guidance and support throughout my master's program. Her expertise and encouragement helped me to complete this research and write this thesis. I am very happy with my choice to pursue graduate studies at McGill University in the Department of Experimental Medicine, and I know my time spent here with Dr. Loiselle and the other members of the Loiselle Lab will be instrumental to my future endeavors.

I would also like to thank, Dr. Justin J. Sanders, and Dr. Christine Maheu for serving on my thesis committee. I am sincerely grateful for their thoughtful guidance and helpful feedback during my M.Sc. journey. I must also thank Dr. Donna Senger for her patience, kindness, and informative support navigating committee meetings and thesis organization. I am also incredibly grateful to the Rossy Cancer Network for providing me with the opportunity to conduct my research through the financial support of the Kuok Fellowship.

I would also like to thank Cyril my partner, my friends, and my family for their love and support during this process. Without them, this journey would not have been possible.

Furthermore, I would like to extend my sincere gratitude to all of the participants in my study. Their willingness to share their experiences and insights has been invaluable to my research and has helped to make this thesis a success. Thank you for your time and contribution.

Contribution of Authors

Conception and design of the study was done by myself, Justine Albert (JA), and my supervisor, Dr. Carmen G. Loiselle (GL). Data analysis and interpretation was done by JA and CL. All chapters of this thesis were written by JA, with feedback from CL. Additional input was given from thesis committee members Dr. Justin J. Sanders and Dr. Christine Maheu.

Clarification of Terms

Informal or Family Caregiver

I will use the term *"caregiver"* to indicate an *informal or family caregiver*. Informal or family caregivers, as described on the Québec government website, are individuals who help someone within their close network, suffering from temporary or enduring physical, psychological, or other disabilities (Gouvernement du Québec, n.d.-b). These caregivers have a close emotional connection, whether familial or otherwise, with the individual they care for (Gouvernement du Québec, n.d.-b). Caregivers can provide support sporadically or continually and can vary in duration (Gouvernement du Québec, n.d.-b).

End-of-life care (EOL):

End-of-life (EOL) care encompasses the medical assistance and emotional support provided during the phase leading up to death. This care extends beyond just the final moments, addressing the extensive care needed by many who live with chronic illnesses for extended periods leading up to their passing (U.S. Department of Health and Human Services, 2022). While the specifics of end-of-life care can differ based on individual preferences and needs, certain core principles such as respect, participation, and compassion remain paramount (McGill University Health Centre, n.d.).

As stated by both the McGill University Health Centre and Quebec's legislation on end-of-life care, every individual nearing the end of their life is entitled to care that prioritizes their dignity, autonomy, and specific needs, and should include prevention and relief of suffering. The comprehensive care approach includes options like palliative care, advanced medical directives, medical assistance in dying, and palliative sedation until death, to which every individual has a right (McGill University Health Centre, n.d.; Gouvernement du Québec, n.d.-a).

Natural Death

Natural death is defined as death occurring in the course of nature and from natural causes as age or disease as opposed to accident or violence. Also, defined as a non-hastened death that can include palliative care. (Laperle, Achille, & Ummel, 2022). Medical Assistance in Dying and palliative sedation until death are distinct from decisions to refuse or cease life-sustaining treatments, which allow a natural death (Mishara & Weisstub, 2013).

Palliative care

Palliative care is a comprehensive approach that focuses on supporting individuals of all ages with severe illnesses, encompassing not only medical professionals but also unpaid caregivers in its ambit (Government of Canada, 2023). Embracing a unique philosophy, this form of care strives to humanize the treatment experience for both the patient and their family. As per the World Health Organization (WHO) (2023), palliative care seeks to holistically manage patients whose conditions are beyond curative treatments, emphasizing pain management, symptom control, and addressing psychological, social, and spiritual concerns. The ultimate objective is to ensure the highest achievable quality of life for the patient and their family (WHO, 2023). Moreover, the WHO (2023) highlights that this care approach recognizes dying as a natural process, without attempting to expedite or delay it, and provides a robust support system to help patients lead an active life till the end.

Medical Assistance in Dying (MAiD)

Medical Assistance in Dying (MAiD) was legalized in Canada in June 2016, and is a practice where healthcare providers, such as physicians or nurse practitioners, administer specific medications to a patient, upon their request, with the intent to end their life and alleviate suffering (Government of Canada, 2023; Boivin et al., 2019). MAiD is for adults who face unbearable suffering and includes two tracks one for a person whose natural death is reasonably foreseeable and another track for persons whose natural death is not reasonably foreseeable (Government of Canada, 2023). Both tracks have a list of particular safeguards such as that a request for MAiD must be made in writing, two independent doctors or nurse practitioners must provide an assessment to confirm eligibility, the person must be informed that they can withdraw their request at any time and there are a few others that depend on which track you fall under (Government of Canada, 2023).

Palliative sedation Until Death (PSUD)

Palliative Sedation Until Death (PSUD) refers to the ethically administered use of sedatives to reduce consciousness, aiming to relieve unmanageable symptoms that persist even after repeated interventions, often termed as refractory symptoms (Meneszes et al., 2019; Booker & Bruce, 2020). Such symptoms might encompass ailments like pain, delirium, dyspnea, and nausea (Bruinsma et al., 2014). Palliative sedation is a last resort for terminally ill cancer patients experiencing continuous and intolerable suffering despite various therapeutic attempts to relieve suffering and whose life expectancy is measured in weeks (Eun et al., 2017). PSUD is simply intended to reduce a patient’s level of consciousness to the extent that suffering is no longer perceived and generally does not hasten death (Eun et al., 2017).

Chapter 1: Introduction

A family or informal primary caregiver is defined as a person close to a patient, typically a spouse, adult child, or friend who is actively involved in caring for the individual affected by illness, by providing physical, psychological, instrumental, financial, and/or social support (Grande et al., 2018; Ugalde et al., 2019; Dillon, 2016; Smolej et al., 2022; Goldberg et al., 2019; Laperle, Achille, & Ummel, 2022). Informal caregivers contribute to care throughout the illness trajectory including end-of-life, providing substantial hours of care, often offsetting health service costs as well as facilitating health-related decision-making (Grande et al., 2018). Due to this important role, caregivers often experience unique unmet needs as well as psychological burden and distress (Kissane, 1999; Bevans & Sternberg, 2012; Areia et al., 2019; Thangarasa et al., 2021; Turcotte, 2013; Sanderson, 2020). In fact, informal caregivers of patients with advanced illness report levels of distress that are equal to or greater than what is reported by patients themselves (Thangarasa et al., 2021, Turcotte, 2012). Despite the fact that approximately 20% of caregivers experience high levels of distress, depression as well as health and psychosocial challenges, there is a lack of research on caregiver experiences, specifically within the end-of-life context of a loved one (Thangarasa et al., 2021; Turcotte, 2012; Sanderson, 2020).

In end-of-life care effective communication between informal caregivers and healthcare providers (e.g., the physician, nurse, pharmacist, social worker etc.) is important for efficient, personalized care as without accurate and clear information, caregivers can experience poor health outcomes (Lowers et al., 2020; Sanderson, 2020). Overall, providing care that is compassionate, respectful, and responsive to patient preferences, values, and needs in collaboration with the clinician, patient, and support network is central to person-centered care (Martinez & Leland, 2015; Loiselle et al., 2019). One important contributor to poor communication is instances of language asymmetry which occurs when the mother tongue of patients, caregivers, and healthcare providers differ (Sanderson, 2020). The amount of asymmetry and how much of a barrier it imposes depends on the familiarity each person has with the language being used or if there is an informal or trained interpreter involved (Sanderson, 2020). However, the risk of misunderstandings, poor communication and potentially medical errors increases with language asymmetry particularly when supporting patients psychologically and discussing sensitive topics which is common in end-of-life care (Sanderson, 2020).

Jackson (1997) described language as “medicine’s most essential technology” as without congruent language, the profession of a veterinarian and a physician would be the same (Bowen, 2001). Language asymmetry between a healthcare provider and a patient not only affects health-related outcomes but also can have detrimental mental health effects as patients and caregivers may be hesitant to ask questions or be discouraged from accessing health services at all (Bowen, 2001; Sanderson, 2020).

In the Canadian context, French-speakers living outside of the province of Québec are considered a language minority, and English-speakers in the province of Québec are considered a language minority. Language-related barriers may further complicate anglophone caregivers’ EOL experiences, as in Québec, English speakers are the official language minority and have been found to experience barriers due to language asymmetry (Sanderson, 2020). According to the Community Health and Social Services Network (CHSSN) in 2016 there were 11,03475 English-speakers in Québec making up 13.7% of Québec’s population (Carter & Pocock, 2022). We know little about the barriers that this population may face due to being a language minority, specifically in the context of being a caregiver at the end-of-life in cases of medical assistance in dying (MAiD), palliative sedation until death (PSUD), and natural death. This is increasingly relevant due to the adoption of Québec’s Bill 96 on June 1st, 2022, entitled the *Act Respecting French, the*

Official and Common Language of Québec, which strengthens Bill 101, the French-language charter from 1977 (Bill 96). Concerns are being raised about the future accessibility of English healthcare in the province of Québec as there are many grey areas around the use of the English language in healthcare in the legislative documents related to Bill 96 (Montreal Gazette, 2022).

The Comprehensive Cancer Experience Measurement Framework (CEMF) is a comprehensive framework that can be used to look at caregiver experiences and will be used to guide the interview questions in the current study (CEMF; Loiselle, Howell, Nicoll, & Fitch, 2019). The CEMF describes four key components of the cancer experience across the illness trajectory: the patient perspective, the family perspective, the patient/family shared perspective, and the multidimensional interactions with the healthcare system (Loiselle, Howell, Nicoll, & Fitch, 2019). This framework is considered more comprehensive than past patient/family experience frameworks and is also informed by previous research highlighting critical elements of patient/family preferences and needs (Loiselle, Howell, Nicoll, & Fitch, 2019; Loiselle & Brown, 2020; Staniszewska et al., 2014; Fitch, 2018). The four components of the CEMF were used to guide the study procedure and analysis, however, the patient perspective was changed to be the caregiver perspective (Loiselle, Howell, Nicoll, & Fitch, 2019). The patient perspective was not included as the study took place after the patient had already passed away.

The objective of this study was to explore how informal caregivers, who identify as English-speakers, experience the end-of-life of a loved one and the resulting bereavement. Furthermore, using an interpretive description approach we examined what we can learn the experiences of participants and what their narratives tell us about EOL care in Québec. The findings were categorized according to the CEMF to: (1*) Individual (internal) caregiver* experiences, (2) *Caregiver-patient* shared experiences and (3) *Caregiver-family* shared experiences, (4) *Caregiver-healthcare system* interactions. The findings also provided insights into the experiences of caregivers who may have faced language-related barriers within this context.

Chapter 2: Literature Review

As the Canadian population ages, there's been a notable increase in chronic life-limiting illnesses, particularly cancer (Stajduhar, 2013; Ahn et al., 2020; Areia et al., 2019; World Health Organization, 2015). Non-communicable diseases such as cancer are a problem worldwide and are a leading cause of death (World Health Organization, 2023). Because of new technologies, people are living longer with these illnesses, putting more pressure on an already stressed post-pandemic healthcare system. At the EOL people with serious illness need physical, emotional, financial, and spiritual support often depending on an informal caregiver to provide this help (Stajduhar, 2013; Barlund et al., 2021; Grande et al., 2018; Woodman, Baillie, & Sivell, 2015). Caregivers were found to provide 80% of home care to people with serious illness in the United States (U.S. Department of Health and Human Services, 2022).

Caregivers are usually individuals close to a patient, such as partners, adult offspring, in-laws or, friends, with a predominant portion being women (Areia et al., 2019; Grande et al., 2018; Ugalde et al., 2019; Dillon, 2016; Smolej et al., 2022; Goldberg et al., 2022; Laperle, Achille, & Ummel, 2022; Brodarty and Donkin, 2009). The role of caregiving is a fundamental component of societal care (Barlund et al., 2021). Their motivations can range from affection, religious beliefs, obligations, societal influences, to negative factors like guilt, with the latter often leading to heightened stress (Brodarty and Donkin, 2009). Throughout a patient's illness, informal caregivers provide extensive hours of care, mitigating healthcare costs and guiding health-related choices (Grande et al., 2018).

This literature review will explore existing research on the multifaceted impact of caregiving, focusing on the physical and psychosocial burdens that caregivers bear, their experiences with bereavement, and the communication challenges they encounter throughout the caregiving process.

Caregiving Health Outcomes

Caregivers have been found to experience both caregiver burden and benefit simultaneously (Luth and Pristavec, 2020). Caregiving, while strenuous, has been found in past research to have positive outcomes (Areia et al., 2019; Brodarty and Donkin, 2009; Luth and Pristavec, 2020). Caregivers often experience personal and spiritual growth, altered life perspectives, the strengthening of relationships with the patient, and feelings of accomplishment (Areia et al., 2019; Brodarty and Donkin, 2009). However, conversely caregivers have also been found to experience heightened psychological ailments like depression, anxiety, and complicated anticipatory grief, as well as physical health issues with heightened mortality risk (Thangarasa et al., 2021; Turcotte, 2012; Areia et al., 2019; Ahn et al., 2020; Grande et al., 2018; Kissane, 1999; Bevens et al., 2012; Sanderson, 2020). In a systematic review of 31 studies, Walbaum et al. (2023) found that approximately one-third of caregivers surveyed reported existential distress, characterized by a significant prevalence of death anxiety, demoralization, pre-loss grief, hopelessness, loneliness, and a feeling of being emotionally unprepared. Moreover, distress levels reported by caregivers can match or even surpass those reported by the patients they care for (Thangarasa et al., 2021, Turcotte, 2012).

The role of caregiving often compels individuals to suppress their own emotional needs, aiming to be the pillar of strength for their ailing loved ones (Brodarty and Donkin, 2009). This often results in reduced social interactions, leading to feelings of isolation (Brodarty and Donkin, 2009). Many caregivers prioritize their patient's needs over personal leisure, diminishing their time with friends and family, and often compromising their employment (Brodarty and Donkin, 2009). Given the stressors and vulnerabilities associated with caregiving, it's pivotal to prioritize the well-being and needs of these informal caregivers.

Caregiver Bereavement

Bereavement is a multifaceted experience that can elicit a wide range of emotional responses, from traditional negative states such as anxiety and depression to positive ones like acceptance and personal growth (Asai et al., 2010; Banyasz et al., 2017). Coping strategies are essential in managing the stress of bereavement, particularly for primary caregivers who must navigate their grief while assuming added responsibilities (Asai et al., 2010; Banyasz et al., 2017). The grieving process is further complicated for some caregivers who experience prolonged grief, impacting their well-being. This condition, variably known as complicated grief or prolonged grief disorder, necessitates the support of social and professional networks (Downar et al., 2020).

The caregiving experience is unique to each individual and significantly shapes their adaptation in bereavement (Pimienta, 2023). Holtslander et al. (2017) observed that factors such as the relationship between the caregiver and the deceased, the nature of the illness and death, and the caregiver's farewell to the care receiver, influence the grieving process (Pimienta, 2023). Additional influences include satisfaction with healthcare interactions during the caregiving journey and aspects of social identity like gender and sexual orientation (Holtslander et al., 2017; Pimienta, 2023). While most caregivers adjust with the support of friends and family, a substantial proportion (~40%) may be at risk for prolonged grief and require additional psychosocial support (Aoun et al., 2015; Pimienta, 2023; Breen et al., 2017).

In Québec, caregivers face a particular challenge due to the limited follow-up support available after the death of a loved one in a home, palliative care unit, or long-term care setting (Pimienta, 2023). This lack of systemized follow-up leaves many caregivers without adequate access to necessary services, placing the onus on them to seek out and navigate grief support systems during a vulnerable time (Pimienta, 2023). There is a need to explore caregiver needs into bereavement with the limited support offered.

Caregiver Barriers to Communication

Clear communication in EOL care between patients, families, and healthcare teams is essential for ensuring that the needs and preferences of terminally ill patients are met and that their caregivers are adequately supported throughout the process (Gerber et al., 2020; Seccareccia et al., 2015; Sanders, Curtis, & Tulsky, 2018). Seccareccia et al. (2015) conducted 46 interviews and 8 focus groups and identified that communication is central to satisfaction and quality care. Their study revealed important elements of effective EOL communication, which included establishing rapport, managing expectations and goals, maintaining informed awareness, actively listening, and facilitating open discussions about mortality (Seccareccia et al., 2015). Sanders, Curtis, and Tulsky (2018) emphasized the necessity of aligning treatment with the patient's known goals and values, particularly in serious illnesses, highlighting the importance of communication in facilitating goal-concordant care. Effective communication was found to be vital for patient safety and encompasses discussing treatment risks, benefits, and uncertainties, as well as responding to emotional needs (Sanders, Curtis, & Tulsky, 2018). Rhodes et al. (2021) emphasized the importance of empathetic interactions between medical professionals and patients, linking these interactions to improved patient outcomes and a reduction in caregiver stress. Similarly, Sanders, Curtis, and Tulsky (2018) highlight the impact of goal-concordant care on the mental health outcomes and overall satisfaction of bereaved caregivers.

Challenges in communication often arise due to the dynamics of power between clinicians and caregivers and can depend heavily on healthcare providers' abilities to initiate and guide EOL conversations (Gerber et al., 2020). Studies have consistently shown that patients and families desire more communication from health providers, especially concerning patients' EOL care preferences and needs (Fried, Bradley, & O'Leary, 2005). Health providers, however, face challenges in initiating conversations about EOL care preferences due to time constraints, privacy issues in busy clinical settings, and discomfort with delivering bad news (Gerber et al., 2020; Minichiello, Ling, & Ucci, 2007; Fallowfield & Jenkins, 2004).

The need for communication extends beyond the patient-healthcare provider interaction; caregivers also require clear information to assist with decision-making, especially when acting as intermediaries or making surrogate decisions for incapacitated patients (Frame et al., 2021; Norton et al., 2019; Shin et al., 2015). Serious illness requires complex decision-making which entails communication about the risk, benefits, and uncertainties of treatment (Sanders, Curtis, and Tulsky, 2018). Gerber et al. (2020) revealed that many older patients prefer to defer decision-making to medical staff, trusting in their expertise, which often leads caregivers to make critical decisions during medical crises. This deference can result in inadequate communication about patient values and preferences, a gap highlighted by Scheunmann et al. (2019), who found that clinician-family conferences frequently lacked sufficient discussion of these essential topics. Caregivers, in particular, benefit from detailed information about the patient's condition to prepare for EOL decisions and potentially avoid the trauma of complicated grief (Norton et al., 2019; Eun et al., 2017). This information is important as research indicates there is often a lack of agreement between what patients prefer and what their caregivers think they prefer, regarding EOL care and preferred place of death (Shin et al., 2015). Discrepancies between patient preferences and caregiver perceptions highlight the need for open dialogue to ensure harmonious decision-making (Shin et al., 2015).

Family dynamics also play a role in EOL communication, with factors such as fear of death, denial, and dependency potentially hindering discussions (Elliott, Gessert, & Peden-

McAlpine, 2009; Gerber, Hayes, & Bryant, 2019). Wallace (2015) noted that while family communication is a known barrier to transitioning to hospice care, the existing research is not exhaustive, particularly concerning the decision-making processes and the role of family communication within them.

Rhodes et al. (2021) emphasize that empathetic communication from healthcare providers can improve patient outcomes and alleviate caregiver stress. Yet, for language minority caregivers, language barriers undermine access to care, quality of service, and satisfaction, potentially leading to adverse health outcomes (Bowen, 2021; Kuzemski, 2022; Yu, Xiao, & Chamberlain, 2021).

In the province of Québec, English-speaking caregivers face significant challenges due to language asymmetry—the mismatch between the primary language of patients and healthcare providers (Sanderson, 2020). Language asymmetry is associated with a host of communication barriers that can complicate the delivery of care and exacerbate the psychosocial burden on caregivers (Sanderson, 2020). Barlund et al. (2021) and Chi and Demiris (2015) identified language asymmetry as a notable impediment to effective pain management and overall home care support. Moreover, these language barriers can lead to misunderstandings, medical errors, inadequate mental health support, and poor patient satisfaction (Bauer & Alegría, 2010; Shabnam, 2022; Bowen, 2021; Kuzemski, 2022; Yu, Xiao, & Chamberlain, 2021; Silva et al., 2022; Chi and Demiris, 2015; Sanderson, 2020; Flores, 2006; Wasserman et al., 2014).

Family members and caregivers often assume the role of interpreters in clinical settings, a practice that can result in incomplete or inaccurate information exchange (Shabnam et al., 2022; Yu, Xiao, & Chamberlain, 2021). This arrangement can lead to treatment delays, non-consensual care, poor adherence to treatment plans, and less provision of palliative care (Yu, Xiao, & Chamberlain, 2021; Shabnam et al., 2022). These interpretive complications can create a sense of powerlessness among patients and caregivers if both are language minorities (Yu, Xiao, & Chamberlain, 2021). Despite the potential benefits of professional interpreters, their use in healthcare settings is hampered by limited availability and concerns regarding the accuracy of translations, especially in sensitive EOL discussions (Rhodes et al., 2021).

As a linguistic minority in a predominantly French-speaking healthcare environment, English-speaking caregivers face barriers that impact care quality and accessibility, particularly in areas outside bilingual zones like central Montréal (Government of Canada, 2022; Sanderson, 2020; Bowen, 2021). The Community Health and Social Services Network (CHSSN) reported that in 2016, English speakers represented approximately 1 in 7 of Québec's population, yet little is known about the barriers faced by this group, particularly when caring for someone at EOL (CHSSN, 2016). Moreover, the enactment of Québec's Bill 96 and Bill 15 raise concerns about the future accessibility of English healthcare services in the province due to uncertainties regarding the legislative documents' stance on English language use (Government of Canada, 2022; Magder, 2022). The Québec Ministry of Health and Social Services (MSSS) recognizes the importance of language in delivering quality services and affirms the necessity of effective communication for ensuring safety and informed consent, as documented by the CHSSN (2022).

Despite high prevalence of distress in caregiving populations, there remains a lack of research focusing on their experiences, particularly in EOL situations (Areia et al., 2019; Thangarasa et al., 2021; Turcotte, 2012; Sanderson, 2020). As reported in past research, it is important to acknowledge that caregivers require assistance, both in practical terms and emotional support (Stajduhar, 2013; Barlund et al., 2021; Grande et al., 2018). This is echoed by The World Health Organization's descriptions of palliative care which underscore the importance of supporting caregivers to reduce caregiver strain (WHO, 2023; Ahn et al., 2020). However, the actual support provided to caregivers often falls short of the holistic approach that palliative care promotes (Ahn et al., 2020).

The rising need for caregiving, in light of the societal aging and the increased prevalence of serious illness, underscores the urgent necessity to better understand how best to support caregiver needs and preferences and the effect of language barriers on caregiver experiences (Areia et al., 2019; Ahn et al., 2020; Sanderson, 2020). It is also important to examine the experiences of bereaved caregivers, how EOL experiences affect their grief, and the adequacy of follow-up support and services for bereaved caregivers in various regions Québec.

With this in mind, the research question guiding the current study is: How do informal caregivers, who identify as English speakers, experience the end-of-life care of a loved one and the subsequent bereavement period, and what are the implications of their language minority status on this experience?

Comprehensive Cancer Experience Measurement Framework

The current study utilizes the Comprehensive Cancer Experience Measurement Framework (CEMF), as formulated by Loiselle et al. (2019), to systematically examine the experiences of caregivers at the end of life. This framework, grounded in person-centered care (PCC), advocates for healthcare that is respectful, responsive, and customized to fit the unique needs, values, and preferences of individuals within cancer care settings (Loiselle et al., 2019).

The Cancer Experience Measurement Framework extends beyond traditional patient experience models by encapsulating four pivotal domains: the patient perspective, the family perspective, the integrated patient-family perspective, and the dynamics of interaction with the healthcare system (Loiselle et al., 2019; Loiselle & Brown, 2020; Staniszewska et al., 2014; Fitch, 2018).

The framework was adapted for the study to reflect caregiver experiences rather than patient experience, which to our knowledge is an adaptation that has not been previously reported in the literature. This modification allows for an exploration of the multidimensional experiences of caregivers, ranging from internal experiences to their shared experiences with the patient and other family members, as well as their interactions with healthcare teams and systems. This research aims to examine these four domains separately, providing a segregated analysis of the caregiver's role, which remains unexplored to this extent.

Chapter 3: Methods

For this master’s thesis study, an interpretive qualitative descriptive approach was used, relying on semi-structured interviews to collect verbatim data regarding the experiences of English-speaking informal caregivers in Québec who cared for a loved one at EOL. This approach was considered appropriate given the study’s research question and objectives as mentioned above- namely the in-depth exploration of participant experiences, feelings, and perspectives to enhance our understanding of the understudied topic of informal caregiver EOL experiences. This study was approved by The Faculty of Medicine and Health Sciences Institutional Review Board (IRB) at McGill University in January 2023 (File Number: 22-11-079) as research conducted for an original master’s thesis.

Participants

Potential participants who self-identified as English-speaking primary caregivers were invited to take part in the proposed study. Inclusion criteria were being 18 years or older, self-identifying as English-speaking, having unrestricted access to internet and an electronic device able to complete video calls or phone calls, self-identifying as the primary informal caregiver of their loved one who died by MAiD, PSUD, or natural death with or without palliative care. A loved one refers to a spouse, parent, adult child, peer, or others that someone has a sustained relationship with.

A purposive sample of participants (N = 16) was recruited from Québec in various regions where palliative/end-of-life services are less likely to be available in English. Initially, we aimed to recruit 12 to 15 participants. We selected our sample size based on the concept *Information Power*, which suggests that the richer and relevant information a sample holds, fewer participants are needed in qualitative studies (Malterud, Siersma, & Guassora, 2016; 2021).

Although Montréal has more English services available compared to other regions in Québec, there have still been barriers found in accessing English health services according to the Community Health and Social Services Network (CHSSN) website (https://chssn.org/). We, therefore, did not limit our recruitment to any specific regions of Québec. We learned the availability of English services by asking participants during the interview "how accessible services were in English". We recruited participants who spoke English and were unable or less comfortable speaking French than English within healthcare settings.

Study Design

An exploratory qualitative design was used to gather in-depth recording of individual accounts.

Procedures. Several complementary recruitment strategies were deployed to recruit participants. By recruiting through a variety of organizations based in different areas around Québec we aimed to have a representative study sample for English-speaking caregivers in Québec. For instance, CHSSN which supports English-speaking communities in Quebec assisted by emailing a recruitment flyer with a QR code for the study consent form (Appendix A) to the 70 organizations in their network, by placing the flyer in their monthly newsletter and by allowing me to present the study at their annual CHSSN Senior Wellness Centre Retreat. We also recruited participants through Hope & Cope – a Montréal-based community volunteer organization where bereavement groups meet regularly. We also used the snowball recruitment method by asking participants to publicize the study to other potential participants who meet the eligibility criteria. Past research is mixed on the correct timeframe to conduct research with bereaved caregivers as it is dependent on the person and whether they experienced complicated grief or not for this reason we did not limit eligibility to a specific time frame (Antonacci, 1990; Bentley & O'Conner, 2015; Butler et al., 2019;

Johnson, 1988; Miles, 1985). The virtual consent form sent to participants was created with Qualtrics, a secure web-based electronic data capture system (Appendix B).

The interviews were conducted virtually on Zoom (camera on or off) or by phone, there was also an option of in person, at the Dialogue McGill conference room located at 550 Sherbrooke Street West, Montréal, Quebec. Conducting the interviews through Zoom or by phone was the preferred mode of communication. These lasted between 60 and 90 minutes. Interviews were audio-recorded and transcribed verbatim. A socio-demographic self-report questionnaire was completed by participants after the interview through Qualtrics or verbally if preferred (Appendix C). A semi-structured interview guide was used by the interviewer (JA) to ensure that all relevant issues were explored (Appendix D).

Data Collection

The interview questions focused on the participants experiences with decision-making in the context of MAiD, PSUD, or ND, their preferences at EOL, and their experiences communicating with the healthcare team before and after the death. This aligns with the notion that participants are the "experts" of their experiences and the researcher/interviewer must, therefore, assume the role of learner (Buckle et al., 2010). The interview guide followed the three-segment plan outlined by Galletta and Cross (2013). The first segment included open-ended questions focusing on the experiences of participants with the goal of generating unanticipated data. Segment two included questions of greater specificity related to the research goals. The third and final segment concluded the interview by revisiting the opening narrative and discussing more theoretical connections. A distress protocol (Appendix E) was also developed to support participants through the sensitive nature of the interview but did not need to be employed.

Data analysis

Directly after each interview, the interviewer (JA) made notes of the central ideas discussed. The interview recordings were then transcribed into text using an AI service called Rev. JA reviewed the transcriptions for accuracy and anonymized them to protect the participants' identities by removing all names and personal details.

Sociodemographic data, which included age, sex/gender, and ethnicity, were analyzed using Excel. For the qualitative analysis, JA employed an interpretive description approach, developed by Sally Thorne (2016). This approach is well suited for applied health research and is flexible allowing the researcher to concentrate on the practical applications for participants (Thorne et al., 2004).

Using NVivo12 software, JA initially conducted an inductive thematic analysis. This involved coding the transcriptions to identify recurring patterns in the participants' accounts (Ryan & Bernhard, 2003; Tracy, 2013; Thorne & Sandelowski, 2016). After coding, JA examined the emerging themes and sub-themes to find those most relevant to clinical practice and the central research question (Thorne & Sandelowski, 2016).

Another master’s student (YK) reviewed these themes and provided feedback. Any differences in interpretation were discussed between JA and YK. Following this, JA collaborated with her supervisor, CL, to refine and further interpret the data. Together, they narrowed down the codes and integrated the results into the Comprehensive Cancer Experience Framework (CEMF), all the while adhering to the principles of the interpretive description approach to enhance clinical practices and caregiver support in the context of MAiD, PSUD, or natural death.

Chapter 4: Findings

The overall structure of the findings herein is informed by the Comprehensive Cancer Experience Framework (Loiselle et al., 2019) which is a lens in which to look at how cancer-related experiences can be construed at both individual and shared domains. In the context of informal caregiving at end-of-life (EOL) these include: (1) *Individual (internal) caregiver* experiences, (2) *Caregiver-patient shared* experiences, (3) *Caregiver-family shared* experiences, and (4) *Caregiver-health care system* interactions. This chapter is divided into these 4 domains encompassing the trajectory from caregiving to bereavement. The in-depth interviews and verbatim transcript analysis led to sub-themes subsumed under each domain with the overarching goal of exploring English-speaking caregivers' EOL-related needs, preferences, and values while caregiving and into bereavement.

The specific study domains and sub-themes can be found in Table 1.

Table 1. Study four main domains according to the cancer experience framework (Loiselle et al., 2019) and related sub-themes

1. Individual (internal) caregiver experiences
Needs for relevant EOL information
Roles and identity in caregiving
Self-blame
Caregiver perspectives on MAiD and PSUD
2. Caregiver-patient shared experiences
Interplay between patient needs and caregiver wellbeing
Preference for location of death
3. Caregiver-family shared experiences
Family EOL decision making
Family care support
4. Caregiver-healthcare system interactions
Goal-Concordant Care
Communication and information management
Navigating the healthcare system
Transition to EOL
Misconceptions of EOL
Language barriers and discrimination

Participant Characteristics

Sociodemographic data for all study participants (N = 16) are detailed in Table 2. Most (94%) were females, 82% were aged 50 years and older with a quarter of the sample between 70 and 80 years old. Regarding employment status, 63% were retired. Spiritual and religious affiliations were reported among half of the sample. In terms of ethnic background, 75% reported being Caucasian of European descent, two identified as Indigenous, one as Asian, and one as Middle Eastern. Geographically, participants were distributed across regions of Québec, including Montréal, Montérégie, Laurentides, Outaouais, Chaudière-Appalaches, and Gaspésie, with one participant residing in Prince Edward Island during the study but who provided prior EOL care in Québec.

Language proficiency, as reported by participants and categorized according to LinkedIn's language proficiency definitions (Appendix F), revealed that English was the native language for all participants. Regarding French language capabilities, 25% (i.e., n = 4) had less than basic proficiency, unable to converse in French; another 25% reported basic knowledge, capable of simple, brief conversations; 38% (i.e., n = 6) reported a conversational level of proficiency, comfortable with daily exchanges but not with complex medical terminology or discussions; and two participants were fluent in French. The participants fluent in French acted as interpreters for their non-fluent care recipients and were thus included in the study.

Regarding the context for the deceased, 94% (i.e., n = 15) had died within the previous five years, with 69% (i.e., n =11) having died in the past two years. Causes of death were reported as natural with palliative care in 44% (i.e., n = 7), natural without palliative care in 31%, (n = 5), PSUD (Palliative Sedation Until Death) in 13% (n =2), and two of the participants loved one's received MAiD (Medical Assistance in Dying). The place of death for eight of the deceased patients was in a palliative care center, with two who died at home, while the remaining six patients died in a hospital or a senior residence.

Table 2. Sociodemographic Characteristics of Participants (N = 16)

Characteristics	n	%
Gender		
Female	15	93.7%
Male	1	6.3%
Caregiver Age		
20-30	1	6.3%
31-40	1	6.3%
41-50	1	6.3%
51-60	3	18.8%
61-70	6	37.5%
71-80	4	25.0%
Relationship to Deceased		
Spouse	8	50.0%
Parent	6	37.5%
Other	2	12.5%
Caregiver French Language Ability		
No Knowledge	4	25.0%
Basic Knowledge	4	25.0%
Good conversational (lack of medical terminology)	6	37.5%
Very good/fluent	2	12.5%
Patient French Language Ability		
No Knowledge	5	31.3%
Basic Knowledge	3	18.8%
Good conversational (lack of medical terminology)	1	6.3%
Very good/fluent	7	43.8%
Work Status		
Retired	10	62.5%
Employed	4	25.0%
Unemployed/On Disability Leave	2	12.5%
Marital Status at time of death		
Married/partnered	4	25.0%
Divorced/widowed	9	56.3%
Single	3	18.8%
Children		
Yes	9	56.3%
No	7	43.8%
Ethnicity		
Caucasian (European ancestry)	12	75.0%
Indigenous	2	12.5%
Asian	1	6.3%
Middle Eastern	1	6.3%
Highest Level of Education		

High school	1	6.3%
CEGEP	2	12.5%
College Diploma	4	25.0%
University Degree	6	37.5%
Graduate Studies	3	18.8%
Region in Québec		
Montréal, city, and region	4	25.0%
Montérégie	4	25.0%
Laurentides	1	6.3%
Outaouais	4	25.0%
Chaudière-Appalaches	1	6.3%
Gaspésie	2	12.5%
Reason for Death		
Cancer	10	62.5%
ALS	1	6.3%
Dementia	2	12.5%
Dementia and Cancer	2	12.5%
Other (Frailty)	1	6.3%
Location of Death		
Home	2	12.5%
Palliative care center	8	50.0%
Hospital	2	12.5%
Senior residence (government)	3	18.8%
Senior residence (private)	1	6.3%
End-of-Life Care provided		
Medical Assistance in Dying (MAiD)	2	12.5%
Palliative Sedation Until Death (PSUD)	2	12.5%
Natural death with palliative care	7	43.8%
Natural death without palliative care	5	31.3%
Time Since Death		
< 1 year	5	31.3%
1-2 years	6	37.5%
3-5 years	4	25.0%
> 5 years	1	6.3%
Length of time caregiving		
< 1 year	7	43.8%
1-3 years	5	31.3%
>3 years	4	25.0%
Spirituality /Religious Beliefs		
None	8	50.0%
Christian	3	18.8%
Jewish	1	6.3%
Spiritual	4	25.0%

Note. N= 16. Participants were on average 60.2 years old (SD= 14.7).

Note. All participant's native language is English.

Caregiving Context

Before discussing the four main domains of caregiving experiences (Table 1), it is important to describe the caregiving context, which includes different environments, geography, and sociopolitical contexts that can impact EOL experiences. For instance, caregivers living in rural or suburban areas, caregiving during the COVID-19 pandemic, and changes in Québec's health care and language policies can pose challenges for caregivers. These challenges include isolation, logistical, financial, and emotional challenges. One participant expressed concern regarding living alone in a rural setting during the COVID-19 pandemic with the closest neighbours being several kilometers away: *"My kids were worried. They wanted me to move closer into town… they did worry about me being alone, and especially during the COVID, and everything else." [F.M. (Female, 68, cared for husband)].*

Other participants described having to drive long distances to visit doctors and hospitals. One participant stated, *"We have to go all the way up to town, which is an hour's drive to see his doctor" [C.D. (Female, 75, cared for husband)].* Another participant said *"I [She] had to drive and stay over in Montréal for my [she] husband's treatments and tests" [R.B. (Female, 73, cared for husband)].*

Caregiver narratives highlight that non-urban settings pose significant challenges, including the need for long-distance travel, securing overnight accommodations in urban areas, and a lack of support close by, all of which require extra planning, time, and resources.

Furthermore, caregiver experiences during COVID encountered additional challenges, affecting care provision and bereavement. Participants (9/16) reported added responsibilities due to the pandemic as reduced healthcare staffing and resources prolonged medical appointments, tests, and treatments.

> *"It was partly the frustration of the lock downs to that, you know, we couldn't get more services in [the house] and the care fell to me totally" [R.B. (Female, 73, cared for husband)].*
>
> *"In the middle of COVID I couldn't leave him alone so I couldn't go pick up equipment that he needed […]They were giving me a hard time getting this equipment and delivering it even the doctor was frustrated." [L.T. (Female, 64, cared for husband, MAiD)].*

Participants also noted lower social support due to COVID restrictions in healthcare settings, a stark contrast from pre-pandemic times. While understanding the necessity for restrictions, many felt that these could have been better balanced to maintain some social interactions.

> *"Even the friends were limited, because we were in the middle of COVID… it was a very, very isolating time" [L.T. (Female, 64, cared for husband, MAiD)].*

Participants reported heightened stress while protecting their loved ones from COVID-19, navigating access to vaccines, and preventing infections. Participants often imposed restrictions on interactions for themselves, close family members and their ill loved one. In addition, a participant noted that the contraction of COVID-19 hastened her loved one's physical decline. These accounts highlight the dual burden participants faced in managing care and safeguarding against the virus.

In addition to the pandemic, Quebec's recent legislation, including Bill-15 (a recently proposed healthcare reform) and Bill-96 (a language reform that is now law), which may restrict access to English-language healthcare services was addressed by nine participants as causing additional distress while caregiving. Participants shared concerns about increased difficulties in obtaining services in English, such as issues with government websites, accessing medical records, and finding English-speaking doctors. These language barriers prompted six participants to consider moving to Ontario to ensure better access to services.

Findings

In terms of in-depth interview data directly relevant to the research question, salient narratives emerged with approximately 365 relevant quotes identified. With regard to the four domains of the Comprehensive Cancer Experience Framework a significant number of quotes related to the *caregiver-healthcare system* interactions domain, while fewer quotes were obtained for the *caregiver-family* shared experiences domain. Among the participants, three reported positive end-of-life (EOL) experiences and "healthy" grief progression. In contrast, four participants recounted negative EOL care experiences in relation to symptoms of complicated grief. The remaining nine participants described EOL experiences as mixed, noting both positive and negative aspects and exhibiting varied bereavement experiences. For instance, participants reported that when communication did not align with their needs, preferences, and values, it resulted in suboptimal EOL experiences, sometimes exacerbating symptoms of complicated grief. Notable communication challenges highlighted by the majority of participants were the absence of clear information about the dying process, palliative care options, and support resources (i.e. homecare support services, and bereavement support). These communication difficulties were amplified by factors such as language barriers, and context including geographic isolation, the complexities of the COVID-19 pandemic, and the implications of recent Québec legislation (Bill-15/96) as described above. Relevant quotes are presented below according to each of the four domains of participant experiences.

(1) Individual (internal) caregiver experiences including needs and preferences

The first domain addresses the inner experiences of caregivers as these relate to EOL issues and care. Key themes include the importance of tailored and relevant EOL information, how the caregiver role can conflict with other personal roles, the dynamics of self-blame, and caregiver perspectives about MAiD and PSUD.

Needs for tailored and relevant EOL information. Caregivers' needs for EOL-related information (including seeking and receiving the information) vary according to their preferences and evolving needs as EOL care decisions are complex. As discussed by Loiselle (2019), health information seeking behaviours can range from intense to active avoidance. About half of participants demonstrated intense information seeking (7/16) - wanting to gather as much information as possible on their own. One participant said, *"I just worried about everything and wanted to understand everything." [F.M. (Female, 68, cared for husband)].*

Similarly, B.T. (Female, 23, cared for uncle, MAiD) did in-depth research on ALS to better understand the disease.

> *"Yeah, ALS, we did a lot of research, on the internet ourselves…so when he was diagnosed at first, I feel like the main focus was just on getting to know ALS and researching it and educating ourselves on it... So, we were starting to just get to know the illness and everything about it." [B.T. (Female, 23, cared for uncle, MAiD)].*

Roles and identity in caregiving. Participants also recounted how the dual role of family member and caregiver can be emotionally and physically demanding. One participant described how caregiver duties overshadowed her role as a wife.

> *"I wasn't his wife" […]* with husband saying, *"this is my favorite nurse". "Me. I was his favorite nurse. I wasn't his wife anymore. So that was taken away from me […] Well, I don't think it bothered him, but it bothered me a lot" [H.G. (Female, 67, cared for husband)].*

Moreover, P.N. (Female, 38, cared for mother) discussed balancing three care roles. *"And I think at some point it was a little bit, I think the difficulty for me was finding the* *balance between being a daughter, a caregiver, and being a mother" [P.N. (Female, 38, cared for mother)].*

Self-blame. Many participants recounted feelings of self-blame and failure, questioning whether they could have done more for their significant other. This is exemplified by one participant who expressed regret for not keeping her husband at home, despite his plea.

> *"I feel like I let him down. I feel like I you know; I feel like I could have done better. I could have kept him at home […] I just feel like I failed him." [C.D. (Female, 75, cared for husband)].*

This sense of guilt and regret regarding EOL care decisions was echoed by another participant who struggled with guilt for postponing MAiD past the holidays and regretted consenting to a last-minute catheter insertion when her ill loved one was always adamant, he did not want one. Similarly, another participant regretted creating unrealistic care expectations due to initial "over caring". Other participants expressed frustration at not meeting their desired standard of care as demonstrated by one participant who stated: *"And, and I had to call the CLSC. He didn't want to go to the hospital. But I had no choice. I couldn't lift him anymore." [C.D. (Female, 75, cared for husband)].*

A recurring theme was a sense of failure by witnessing patients 'giving up' or accepting death. This is illustrated by one woman who found her husband's choice to cease treatment distressing: *"But it was very hard on me knowing that he was giving up and I was going to lose him." [F.M. (Female, 68, cared for husband)].*

Another participant was troubled by her mother's sense of having nothing to live for – not considering that she could be there for her daughter – the carer.

> *"I remember she said to me, I don't have much to live for. But I was devastated by that […] It was very, very sad that she didn't have anything to live for. And I would think, don't you want to live for me?" [J.T. (Female, 58, cared for mother)].*

Caregiver perspectives of MAiD and PSUD. A few participants opposed MAiD (N=2), expressing that it might be more convenient for the health care system to "rush their death" [C.D. (Female, 75, cared for husband)]. One participant said *" I have a few concerns about MAiD...I want our healthcare system to care for people. And to not take an easy way out". [J.T. (Female, 58, cared for mother)].*

Despite some reservations, most participants supported MAiD as a compassionate choice for those suffering. Others underscored that, their views on MAiD and PSUD were more positive after witnessing patient suffering while dying.

> *"So, I think if there's no quality of life, they're suffering, they're in pain, they're bedridden, they're not eating, then I completely understand the decision." [B.T. (Female, 23, cared for uncle, MAiD)].*

The initial domain focuses on the internal experiences of participants in the context of their caregiving role at the EOL. It revealed that participants like their ill loved one have information-seeking preferences for medical information ranging from active to passive. Participants also grappled with their roles and identity, with some feeling they had lost their previous relationship dynamics due to their caregiving responsibilities. A common emotional response among participants was self-blame, with many questioning their decisions and actions during the caregiving process. These insights underscored the internal challenges participants faced and serve as a backdrop for discussing the shared experiences between participants and their loved one, the next study domain.

(2) Caregiver-patient shared experiences

The second domain focuses on the shared experiences of participants and their loved one as EOL care necessitates a balance between the individual needs, preferences, and values of caregivers and those of the person they are caring for. The themes in this domain describe the participants role advocating for their ill loved one and the responsibility participants felt to ensure their loved one's EOL wishes were met.

Interplay between patient needs and caregiver wellbeing. This theme encapsulates the challenges participants faced of supporting their loved one physically and emotionally. This dual demand often resulted in participants neglecting their own needs, leading to burnout especially as their loved one's illness advanced, leading to relational strains and diminishing the participants capacity for self-care.

One participant articulated the evolving nature of caregiving, noting a decline in gratitude from her husband over time.

> *"At the beginning, he was very appreciative of my care for him […]But as time went on, there was less of that […]He could be quite demanding of me and not particularly thoughtful. So that was quite difficult." [J.K. (Female, 76, cared for husband, PSUD)].*

Another participant expressed the constant caregiving demands placed on her, leaving her with no opportunity for self-care, explaining that *"there was no time to take care of me. I mean, he demanded so much attention" [H.G. (Female, 67, cared for husband)].*

The challenges of balancing the ill loved one's needs and the wellbeing of the participant were further highlighted when participants were unable to manage caregiving tasks due to burnout but their loved one did not want institutional care. This was demonstrated by a participant who recounted her husband's resistance to going to a palliative care facility saying "no, I want to die at home" *[H.G. (Female, 67, cared for husband)]* and the tension this caused with the participant getting help from the healthcare team to try and convince her husband to no avail, stating that *"they tried to convince him because they said,*

> *your wife will not be able to do it on her own... It will be 24 hours a day, which it was." [H.G. (Female, 67, cared for husband)].*

Last, another participant illustrated the mistrust and consequent vigilance some participants felt towards professional care, with the participant continuing to care for her husband at home to the detriment of her wellbeing as she stated she "*didn't trust them to take care of my [her] husband." [F.M. (Female, 68, cared for husband)].*

This theme underscored the overwhelming nature of caregiving with the participants dedication to their loved ones needs and preferences at times overshadowing their own wellness and causing relational tension between the participant and their loved one.

Preferences for location of death. Many participants discussed conversations and decisions about the location where their loved one wished to die. These conversations often were difficult particularly when loved one's wishes were not in line with the participants capacity and/or preferences. Most participants reported that their loved ones wished to die at home (12/16) yet only two were able to die at home.

> *"They offered the palliative care [hospice]. And he [her husband] kept on saying no. And I kept saying, excuse me, I want help. If not him, I need it because I don't know what to do with him anymore." [H.G. (Female, 67, cared for husband)].*

Many participants (13/16) confronted scenarios where the physical toll of caregiving, compounded by medical complexities and mental health concerns such as dementia or the need for specialized equipment, became challenging. One participant stated she "*wanted to take care of him, but I [she] was at the point where I could hardly take care of him." [L.T. (Female, 64, cared for husband, MAiD)].* Another participant said:

> *"And that's what I did. Because I knew I couldn't take care of him anymore. I, my biggest concern was that he would fall, and I wouldn't be able to pick him up." [P.C. (Female, 76, cared for husband)].*

P.N.'s (Female, 38, cared for mother) account of post-stroke care requirements highlighted how physical limitations of the participant and their loved one led to the difficult decision of transitioning to a care facility, underscoring the emotional and logistical complexities caregivers face when home care is no longer possible.

Another participant described the difficulty of realizing her mother's discontent at the location of her death. This participant perceived her other's refusal to eat as an act of protest.

> *"I hadn't fully realized how much she didn't want to be in a residence kind of thing. Because what she did was, she just started reducing, like, she just kind of almost stopped eating, she didn't completely stop eating…And that was really hard" [J.T. (Female, 58, cared for mother)].*

Shared decision-making between the participants and their loved one regarding the place of death was challenging with most participants wanting their loved one to die at home. However, the demanding nature of caregiving meant that only a few participants were able to honor this preference, leading to emotionally charged discussions when the participants abilities did not align with the wishes of their dying loved one.

The domain *caregiver-patient shared experiences* reported the dynamics of EOL decision-making and communication between the participant and their dying loved one. This domain described the challenges participants experienced balancing the physical and emotional demands of caregiving with their loved one's EOL needs and preferences particularly the dying loved one's preferred location of death. The next domain will focus on the participants interactions with other family members when making EOL decisions.

(3) Caregiver-family shared experiences

An important aspect of EOL experiences lies in the shared experiences of the caregiver and family. The interviews revealed the supportive roles family members play, from providing physical support to bridging EOL-related communication gaps for the participant.

Family EOL decision-making. Many participants underscored the influence of family dynamics on EOL decision-making. Participants detailed the familial challenges in choosing between MAiD and other EOL options, noting tensions arising from religious prohibitions against MAiD, as in the case of one family's conflict due to their Jewish faith.

> *"The Jewish religion doesn't believe in MAiD. It was a whole discussion in palliative care. I didn't even know. We didn't know palliative sedation was an option, which by the way, is allowed in the Jewish religion." [F.G. (Female, 47, cared for mother, PSUD)].*

Two participants faced challenges reconciling their personal non-religious support for MAiD decisions with their extended family's religious objections: *"To them [family], it's [MAiD] tantamount to mortal sin type of thing" [L.T. (Female, 64, cared for husband, MAiD)].*

In contrast, another participant noted a supportive family environment without reservations regarding MAiD stating, *"There was no stigma because people are like, he decided to do this" [B.T. (Female, 23, cared for uncle, MAiD)].*

Furthermore, participant J.K. (Female, 76, cared for husband, PSUD) shared her gratitude to her family members who supported PSUD as a compassionate choice.

"I mean the last 24 hours, of course it was extremely difficult doing that, signing the forms and very painful to do that. I think the three of us, the daughters and myself, we knew it was the right thing to do at that point [...] So it really felt, thank God, it felt like a team." [J.K. (Female, 76, cared for husband, PSUD].

Family care support. Participants highlighted how family involvement was important in their ability to provide EOL care. Various participants described the physical challenges of caring for their significant other at home, often requiring support from other family members. For instance, one participant highlighted the need for her son's physical strength to lift her husband.

> *"Near the end, I found it really difficult because I couldn't lift him anymore. You know, I'd have to call my son at all hours to come and help me because he'd fall. And I couldn't pick him up" [C.D. (Female, 75, cared for husband].*

Another participant highlighted how reliance on family was needed. As her husband's condition deteriorated, requiring constant care and frequent morphine administration, the support of her stepson became important. The family's decision to keep the patient at home rather than move him to hospice was made possible through this shared commitment.

> *"When I had trouble getting my husband to the bathroom, I couldn't do that by myself. So, every time he had to go to the bathroom, I'd have to call my stepson, he'd drive over, help me." [D.L. (Female, 68, cared for husband)].*

Six other participants noted that their bilingual family members often acted as interpreters, filling language gaps in service delivery and demonstrating another way participants depended on family for support however this will be discussed below in a section about language barriers.

The domain of *caregiver-family shared experiences* described how family members provided both physical support and communication support. Family dynamics were found to influence EOL decision-making, especially regarding MAiD, where personal beliefs and religious values were either found to create tension or offer a supportive environment. The fourth and final domain expands the focus from participants' personal relationships to encompass their interactions with the broader healthcare system, examining how these dynamics play a role in EOL experiences.

(4) Caregiver-healthcare system interactions.

Caregiver-healthcare system interactions was the domain which was most emphasized by participants. They highlighted the importance of having healthcare professionals deliver care that aligns with the known goals, preferences, and values of both patients and informal caregivers, a concept known as goal-concordant care (Sanders, Curtis, & Tulsky, 2018). Goal-concordant care was viewed by participants as facilitating optimal EOL care. Suggestions to improve goal-concordant care that were discussed by participants was assisting caregivers in navigating the healthcare system, providing accessible bereavement support, and correcting any misunderstandings about EOL processes. Certain participants reported that due to being an English-speaker, language barriers further hindered goal-concordant care as described below.

Goal-Concordant Care. Aligning medical recommendations/treatment with patient/caregiver known goals and values, is key to providing quality EOL care (Sanders, Curtis, & Tulsky, 2018). According to the authors, effective communication is the main pillar of providing goal-concordant care as it allows for shared-decision making among the patient, caregiver, and the healthcare team. In this study, 11 participants reported that poor communication from healthcare providers resulted in suboptimal EOL experiences and 8 of them described experiencing complicated grief. A participant, who lost her husband three years ago, described EOL care as not aligning with her preferences and expectations and in turn described symptoms of complicated grief:

> *"Even today, I can't do anything I'm numb. Most of the time I'm numb and the rest of the time I can hardly do anything it's like I just walk around like a ghost you know, and I have no ambition nothing" [C.D. (Female, 75, cared for husband)].*

Those 11 participants who experienced poor healthcare-related communication reported that insufficient conversations and a lack of information regarding their loved one's prognosis and the available EOL options contributed to negative EOL experiences. One participant *[N.S. (Female, 53, cared for father)]* recounted that due to the lack of EOL options provided she felt that the last *"four days were terrible*" and that she was "just *waiting there for him to die. It was terrible."* Another participant noted that unclear communication about the patient's prognosis resulted in the patient rejecting palliative care and MAiD, clinging to hope for survival until the very end: *"Giving him false hope, because my husband kept on saying, yeah, but [the doctor] said, I have two years [...]He still had hopes of pulling through." [H.G. (Female, 67, cared for husband)].*

Participants were upset when their loved one's wish of where they wanted to die was not met as expressed by one participant who still felt "haunted" by not caring for her husband at home.

> *"Oh no his choices were not respected because he did not want to be shoved off into a home and die in some strange place. He wanted to be at home, but he couldn't. He couldn't because it was too late, you know?... And that's something that haunts me." [C.D. (Female, 75, cared for husband)].*

Furthermore, three participants expressed a wish that, if they had known the limited time left, they might have chosen to keep their loved one at home: *"If I knew he only had a month left, I would have probably tried to stick it out at the house" [N.S. (Female, 53, cared for father)].*

Some participants (5/16) articulated both a sense of guilt and relief when faced with the necessity of the patient's placement in a healthcare institution exemplifying the complexity of EOL decision-making and internal conflict participants experienced when making these decisions specifically regarding location of death.

> *"The doctors [...] were recommending placement. I think that was a difficult time for me. And I felt somewhat guilty, in the sense that here is. On a certain level, I know that this is*

> *probably my mother's worst nightmare. And it's happening. And on one sense, I'm relieved." [J.T. (Female, 58, cared for mother)].*

Another participant underscored how advanced care planning conversations can be disconcerting particularly when there is little rapport with the clinician and when the caregiver prefers to avoid EOL-related information. She recounted, a difficult conversation about resuscitation that took place with a new doctor which left her shocked and upset.

> *"Maybe the family doctor should have talked with him before [...] we don't even know this doctor. And he's like, anybody ever talk to you about end of life and what you would do? And when they were saying about breaking their ribs, I was like, oh my god [...] I don't know if I closed my ears, I didn't want to hear it. It was just like a shock." [N.S. (Female, 53, cared for father)].*

In contrast to participants' negative communication experiences, those who received clear goal-concordant care (5/16) expressed gratitude and satisfaction for the peaceful death their loved one, which was also accompanied by more positive bereavement experiences. A participant described her husband's death process, *"he was calm… and the breathing just stopped"*, she went on to say how she felt "*everything transpired as it should be… I mean, I think that's why I have enough peace with it [...] things just felt right." [R.B. (Female, 73, cared for husband)].* Another participant reported a positive bereavement period because she felt her husband's and her own EOL preferences were respected:

> *"His wishes were met [...] They were supportive of him. Everything happened the way he wanted [...] The Palliative Care Center, the nurses, and the staff and the doctor, were extremely supportive, very loving, very caring [...] they were very attentive to my needs and his needs and the family's needs [...] . I remember the good times together the life we had together [...] I had a lot of support." [P.C. (Female, 76, cared for husband)].*

Communication and information management. Participants often acted as intermediaries between their loved one and the healthcare team when making EOL decisions. Participants described filtering information as a way of managing patients' perceived needs and due to a desire to protect them.

One participant showed a proactive approach to information management. Aware of her husband's fear and her intimate knowledge of his preferences, she requested healthcare professionals to consult her before communicating with him. However, clinicians disregarded participants' preferences to manage EOL information and communicated directly with patients – causing problematic interactions.

> *"He was afraid. [...] I knew him like a book. [...] And I knew that he was not he, he didn't want to hear anything horrible. So, I asked them, I said, talk to me before you talk to him. And you know, I'll decide what you can tell him. Well, I walked in to see him one day, and the doctor and nurse were both standing there telling him that he was dying. I was so angry" [C.D. (Female, 75, cared for husband)].*

Another reported that her father's diagnosis was disclosed directly to him, without informing the participant beforehand distressing both the daughter and her father.

> *"So, then the doctor just starts talking in front of my father about thinking might have lung cancer and he never talked about that. He just told him that his lungs were really sick." [N.S. (Female, 53, cared for father)].*

Another participant asked for MAiD-related discussions to be avoided in the presence of their vulnerable mother, illustrating the challenging balance between honoring patient autonomy, and protecting their mental state.

Other participants felt they had to advocate for the patients' needs and preferences.

> *"So, my role basically was to be his voice. And it felt a lot of times it fell on deaf ears" [E.W. (Male, 61, cared for community member)].*

Navigating the healthcare system. Participants often faced challenges when dealing with the healthcare system, highlighting restricted support and a paucity of logistical information provided to them. Participants frequently cited the complexity and confusion inherent in understanding and accessing supportive resources. Many were unaware of certain types of support, such as CLSC assistance, bereavement services, or caregiver compensation.

Participant F.G. (Female, 47, cared for mother, PSUD) expressed frustration over the lack of information provided by the healthcare team regarding available resources until after her mother passed away.

> *"The social worker basically vomited to me what services I had been eligible for, and I wanted to die because as savvy as I was, I didn't have the capacity to go seek them out at the level I needed." [F.G. (Female, 47, cared for mother, PSUD)].*

Most participants were unaware or could not access caregiver benefits or other support resources. However, four participants, who were also healthcare professionals, navigated the system more effectively and secured caregiver benefits. One such participant, drawing on her professional experience, felt like *"it was an automatic"* to proactively seek out available resources, including caregiver compensation and leave, and initiated contact with a palliative care center, recognizing the potential for the patient's condition to deteriorate quickly.

> *"It was clear for me in terms of support... I had time off to be with her every day [...] I asked the CLSC palliative team to open up her file at the hospice just in case, which was good [...] she was transferred almost immediately when her condition declined." [P.N. (Female, 38, cared for mother)].*

Furthermore, another participant noted that her professional background facilitated a more proactive approach in advocating for her husband, utilizing her knowledge of medical terminology to communicate effectively and ensure the provision of optimal treatment and care.

> *“I was a very, very strong advocate for him... We were able to talk to the oncologists in a very informed way about treatment options... I put my social work hat on, knowing how to push for an appointment or action.” [J.K. (Female, 76, cared for husband, PSUD)].*

Knowledge of and access to bereavement support among participants varied, with geographic location being a significant factor. Participants outside Montréal reported challenges in obtaining grief counseling, with some facing overbooked services leaving them without support. *"There's not even help for people who are going through what I'm going through, there's nothing," [C.D. (Female, 75, cared for husband)]* shared one participant, indicating that none of the grief counselors were taking on new patients. This same participant noted the absence of government or medical team support in this area, reinforcing the sentiment of being "stuck in limbo." Similarly, when asked whether L.T. (Female, 64, cared for husband, MAiD) was informed or offered bereavement support after her husband’s death she responded saying *“Not a chance. It didn’t even blow in the air, okay, I've never even heard of anything.”* Another participant located rurally found it difficult to find grief support due to the distance as she described driving an hour to Ontario for an English therapist until it became too challenging to drive so far. This participant’s experience also highlights limitations to bereavement support due to language barriers which is discussed in more detail in the following section.

In contrast, participants living in Montréal, especially those connected to palliative care centers and Hope & Cope, reported receiving follow-up support after their loved one's passing. This support was perceived as beneficial, though emotionally challenging, facilitating early exposure to grief.

> *“I am one of the fortunate ones. After his death, the palliative home, reached out, offered me all this support. I got a lot of support from them. I'm saying it was very*

> *tough because it's making me face my grief, but it's right up in my face and I have to face it. And I think because of that, I went through the hardest part right then. I mean I still have heart moments now." [H.G. (Female, 67, cared for husband)].*

The preference for in-person bereavement support over virtual means was mentioned by most participants. Moreover, more tailored bereavement groups that considered factors such as age and relationship to the deceased, were suggested as promising ways to better address individual grieving needs.

Transition to EOL. When transitioning to EOL care, many participants, especially those with loved ones affected by cancer, reported experiencing a gap in communication and a lack of seamless transition from active medical treatment to EOL care. Participants reported an inadequacy in the provision of information regarding palliative care and the range of available EOL care options, including MAiD and PSUD.

About a third of participants reported inadequate information regarding palliative care options (5/16), often offered too late or not at all, and a lack of smooth transition from active treatment to EOL. A participant stated that "nobody told her" about her mother's eligibility for palliative care and that she wished the healthcare team would have better explained the various care options. This participant also raised the issue of determining the appropriate time to initiate discussions about palliative care.

> *"I had no idea [...] I didn't know that by definition, having stage four meant she was eligible for palliative services, even though we weren't talking about palliative at the time. I didn't know that. Nobody told me that [...] At what point are people educated about these services [palliative care] because they're not, and when should they be? And nobody sat down and explained to me what the options were" [F.G. (Female, 47, cared for mother, PSUD)].*

This same participant described how delayed palliative care conversations resulted in extending active treatment for her mother causing undue suffering and also exacerbating her emotional distress. The participant cried while saying:

> *"Because I think my mom would have skipped the last chemo and we would've just enjoyed the time she had [...] All we knew is reduce the amount of cancer she has so she's suffering less as opposed to having palliative care to give her good quality of life. But none of those conversations ever happened." [F.G. (Female, 47, cared for mother, PSUD)].*

The same participant [F.G. (Female, 47, cared for mother, PSUD)] goes on to explain that there is a *"huge gap"* between resources offered by the government and caregivers' awareness of these services. She pointed out that while caregiving she *"didn't have the capacity in the moment to go beat down door to seek out*" all the available resources, particularly for complex issues like palliative care discussions.

One participant described the transition from active treatment to palliative care as abrupt and had not been previously discussed with the healthcare team. The lack of subsequent communication contributed to the perception of staff insensitivity.

> *"So, these are things that should have been addressed earlier. I mean, [the oncologist], it's not their first patient that had lung cancer. They must have known the progression. So, I was disappointed with that [...] the way we were, he was just dropped like a hot potato [...] He left the hospital and that's it. No more phone calls from the pivot nurse. No contact with the oncologist. No follow up. Not even with his GP. Nobody got in touch with him. Nobody...He was very upset and needless to say, so was I." [H.G. (Female, 67, cared for husband)].*

Similar to the communication issues regarding palliative care, participants commonly reported not being informed about EOL options such as MAiD or PSUD. Often, when they learned of these options, it was already too late to use them. For instance, R.B. (Female, 73, husband) shared that her husband might have chosen MAiD if they had known about it sooner. Furthermore, five participants and their loved ones had to initiate discussions about MAiD themselves, as healthcare providers did not mention different EOL options.

> *"My mother should not have been the one in March to raise that [MAiD]." [F.G. (Female, 47, cared for mother, PSUD)].*

Some participants reported several challenges in obtaining MAiD, not only because of family disagreements or reluctance but also due healthcare system obstacles. One participant recounted the bureaucratic hurdles that nearly prevented her husband's request for MAiD, which, despite eventually being granted, caused significant stress.

> *"They wanted to wait 10 days and he burst into tears […] They finally relented, and they, they did it ahead of time" [L.T. (Female, 64, cared for husband, MAiD)].*

The decision to pursue PSUD also had its challenges. Only one participant reported being made aware of it.

> *"And so I think at the very end that there's these different, there's MAID, and then there's palliative sedation. So, he was asked if he wanted, now, they didn't actually call it that. They sort of said, would you like to be able to sleep and rest and just not wake up from this? And he said, yes. And then it [PSUD] was discussed with us with the family in some detail." [J.K. (Female, 76, cared for husband, PSUD)].*

F.G. (Female, 47, cared for mother, PSUD) did not know the difference between MAiD and PSUD prior to her mother's EOL care. However, the experience of having PSUD allowed F.G. (Female, 47, cared for mother, PSUD) to find solace in the belief that her mother passed peacefully and with dignity.

> *"It [PSUD] gave her something of dignity about how she wanted to go" [F.G. (Female, 47,cared for mother, PSUD)].*

Misconceptions of end-of-life. Several participants (7/16) recounted the death experience as traumatic, often due to a lack of understanding of the dying process, causing them to misinterpret natural processes such as labored breathing or not eating as distress. Some held the belief that death could not be a peaceful or comfortable experience because of negative associations with the concept of dying. One participant said: *"Even when he was in a coma, he didn't seem comfortable. I don't feel now that someone dying really can be made comfortable... He would moan." [D.L. (Female, 68, cared for husband)].Another participant went on to express disagreement with the term comfort care stating: "But comfort care, they should re-say their word, because there's no comfort care there" [N.S. (Female, 53, cared for father)].*

Furthermore, a participant perceived palliative care as an act of hastened death rather than comfort measures contrasting hospice practices with the belief that the hospice staff "killed" her husband. She recounted:

> *"I know, people go on and on about how wonderful hospice is… this place was a horrible place. He gets in there and it's nice. It's beautiful. The staff seem to be really nice…He was only in there four days. And he died. He died on the fifth day. I couldn't believe it. It was like what happened?... What happened is they killed him. They just decided he's finished. We're just going to dope him up because like he was out of it for the four days. Like we couldn't speak to him." [C.D. (Female, 75, cared for husband)].*

The confusion around loss of consciousness at EOL was also expressed by another participant who did not realize her husband would lose consciousness as this was not explained by the team.

> *"He lost consciousness the last four days, which was hard because I hadn't said everything I wanted to say and not it been a long time. And we knew he was going to*

> *pass, but it was sort of we're surprised when he lost consciousness. He didn't regain consciousness, so that was difficult." [D.L. (Female, 68, cared for husband)].*

Another participant felt unprepared for the symptoms her mother exhibited at EOL, clearly lacking information about the final stage of dementia.

> *"I don't know if that was what happens with dementia patients when they're at that stage where they can't eat anymore, they can't swallow, they lose that ability." [V.T. (Female, 64, cared for mother)].*

This same participant further described emotional and physical impacts of the unforeseen manner of death, emphasizing that there was a lack of explanation provided about natural processes leading to death.

> *"I was upset the whole three weeks when she was dying like that so hard. I couldn't sleep. I couldn't eat. I couldn't stand that. I was just like; this is not right. And yet, there was nobody to talk to about this. I had no idea, nothing. I never heard that before in my life that this is what happened [Referring to the end-of-life symptoms experienced by her mother]." [V.T. (Female, 64, cared for mother)].*

The above theme described participants negative experiences with their loved one's death due to misunderstandings highlighting a gap in communication and education about EOL.

Language barriers and discrimination. Six participants highlighted significant stress from communication struggles with the healthcare team due to language barriers. For these participants, language barriers compounded overall communication challenges limiting goal-concordant care. This is demonstrated by participants whose lack of clarity regarding their loved one's illness trajectory and their decline in health, was a result of language barriers with clinicians along with the other communication challenges mentioned in previous sections. A participant initially thought her lack of preparedness for her husband's death was due to her own denial, however, further discussion revealed that it was largely due to inadequate communication from clinicians, compounded by language barriers.

> *"To me, I felt it [language] was a barrier [...] I never really picked up the language. I felt I really didn't understand everything. Especially about making the end of life. Maybe because I didn't want to confront it...it happened so fast that it became difficult" [F.M. (Female, 68, cared for husband)].*

This was echoed by another participant who reported that clinicians directly discussed EOL planning with her father who had dementia (and did not have the cognitive ability to relay this information) or with her mother who spoke very little French causing confusion for the participant as the primary caregiver.

> *"So, like, at times, when he would go into the hospital, and the doctors would come and talk to him and no family was present, we would never really know like, because he couldn't converse with us and tell us what was going on [...]But so I guess sometimes we were confused, really as to what was going on. . And then if my mother was there, she didn't really even understand what they were talking about." [G.H. (Female, 52, cared for father)].*

Language barriers also compounded some of the challenges experienced by participants, as they often had to interpret medical documentation such as pamphlets and instructions to patients, despite their own limited French.

> *"When [my husband] was getting chemotherapy [...] they handed him a bunch of French pamphlets on how to take care of himself. And [my husband] asks for English ones. And they said, we don't have them [...] I tried to read them. And again, a lot of medical terms, I couldn't understand a lot of it. So, for me, it was like I was just sent a drift" [L.T. (Female, 64, cared for husband, MAiD)].*

Several participants relied on other family members to bridge language gaps and interpret medical information for them. One participant said: *"One of them [the doctors] spoke no English, which was a problem for me. But fortunately, my stepson would come in and he could speak French." [D.L. (Female, 68, cared for husband)].* Two participants had very similar experiences as seen below:

> *"Of course, And then I would get my son to, I'd call my son and say look, you're going to have to talk to them because [...] they can't speak English and I don't understand what's going on. So, he would come, and you know, but he did a lot of the speaking for me, you know?" [C.D. (Female, 75, cared for husband)].*
>
> *"Until they found me a nurse that was pretty English for that, my daughter actually came to help me. Because they know how I am about speaking in French, and I was worried about not understanding everything." [F.M. (Female, 68, cared for husband)].*

The participants mostly required their adult children to act as translators in situations where the EOL loved one, who was bilingual, could no longer communicate. However, in some cases, even when participants themselves had limited French language skills, they would take on the role of interpreter if they were more proficient than their ill loved one. Five of the participants felt that language barriers (between ill loved one and healthcare staff) meant that, as caregivers, they had to be physically present to avoid miscommunication. A participant stated that her presence at appointments and at the palliative care center was "not only as a caregiver, but also as a translator" *[P.N. (Female, 38, cared for mother)].*

Another participant felt the necessity to be present with her husband in the hospital, due to concerns about mistreatment associated with his status as a minority language speaker.

> *"He wouldn't speak up because he was afraid of being shamed about the fact that he doesn't speak French...So he [the patient] said to me [...] I'm probably going to be mistreated if you're not standing there." [L.T. (Female, 64, cared for husband, MAiD)].*

The same participant described experiencing significant distress during her caregiving period, motivated by her desire to maintain home care for her husband, who faced language-based discrimination within the healthcare system. She cited several instances of such discriminatory experiences.

> *"Well, he was stressed, because he worried that he would end up […] in palliative care where no one would understand him. And he worried that if I wasn't standing there, that he would get mistreated. That was a constant worry with him. You know, and, and, you know, in the end, he wasn't there long. But, you know, you've got to remember, he's faced discrimination because he couldn't speak French for many, many years." [L.T. (Female, 64, cared for husband, MAiD)].*

The above participant and three others reported feeling marginalized and facing discrimination because they or their loved one could not communicate in French. The following participant described the disrespect he witnessed in a senior residence.

> *"So, they, they sort of ignored him being an Anglophone. And this man, he was losing his eyesight and his hearing. So, when I went to the administration, the only thing they did was they put a thing on the door in French saying […]can you please speak to this guy in English, he can't see well, because he would get his meals and look at the person and he'd say, well, what am I what am I eating? And they just sort of throw the plate there and leave, you know, so yes, very disrespected in that sense." [E.W. (Male, 61, cared for community member)].*

This was also exemplified by reports of healthcare workers questioning why a participant or their loved one could not speak French, despite a lifetime spent in the province. For instance, one participant expressed this saying, "*We thought we lucked out with a nurse that spoke English except that she basically shamed him the whole time for not being bilingual." [L.T. (Female, 64, cared for husband, MAiD)].*

Furthermore, some participants also faced challenges in navigating the healthcare system and obtaining support resources due to language barriers as exemplified by a participant who explained that *"I [she] tried to get to talk to somebody in English to find out where I'm [she was] going. Because I [she] had to take him there [the hospital] for tests. They wouldn't even give me [her] directions in English." [F.M. (Female, 68, cared for husband)].*

This same participant said she resorted to rudimentary sign language when at the hospital to convey her husband's complex medical needs and opted for home care to avoid the French-speaking healthcare system.

> *"Going to the hospital [...] I'd have to deal with people who didn't speak English and wouldn't communicate. So, for me, I think he felt that it was making it easier for me because we could deal with things together, here at home, and we worked on getting more English around there" [F.M. (Female, 68, cared for husband)].*

However, even when providing home care, she described challenges in finding English-speaking care professionals, which delayed services.

> *"They had to find people to come and help me, but it took long because I don't speak French [...] because they had to find people that could deal with me in English it took longer." [F.M. (Female, 68, cared for husband)].*

Participants also described difficulties accessing bereavement support in their preferred language, experiencing delays and lack of affordable options. One participant explained that she tried to find a bereavement therapist in her area but *"couldn't find one that spoke English." [L.T. (Female, 64, cared for husband, MAiD)].* Another participant wanted to do the bereavement therapy offered by the government but had to wait an extended period of time for an English-speaking therapist.

> *"They have the government therapy that you can go to that gives you six visits for free. I had to wait a couple of months till they found a therapist was available who spoke English for me to go so I waited. He passed away in January, and I didn't see that therapist until I think, May or June." [F.M. (Female, 68, cared for husband)].*

In some instances, however, participants (7/16) experienced efforts from healthcare workers to accommodate their language needs as exemplified below.

> *"People would translate for me through that process, which I appreciate. And even in the palliative care home [...] there who were volunteers who didn't have much English, but they always, they were so well trained, because they always would get somebody if they couldn't communicate, you know." [R.B. (Female, 73, cared for husband)].*
>
> *"Like, they (CLSC) were like Francophones like you heard the big French accent, but they tried their best. And that is something I really appreciated. Because when I texted them, I would text in like English, but I would feel bad because I was like, well, I know they're French, but they would always answer in English" [B.T. (Female, 23, cared for uncle, MAiD)].*

All participants acknowledged that most doctors were adequately bilingual, and the challenges were mainly with other healthcare staff. At times, it depended on geographical location as participants in Montreal (4/16) attending McGill-affiliated hospitals reported few language barriers.

> *"Well, certainly not at the Jewish, because everybody spoke English. The palliative home, there were a few words that maybe I didn't catch because let's face it, medical terms, I don't know in French. But I mean, I tried to understand the best I could, and they tried to explain the best they could." [H.G. (Female, 67, cared for husband)]*

This theme highlighted that participants felt it was important for healthcare providers to deliver EOL care that is consistent with the preferences and values of both patients and caregivers, a practice referred to as goal-concordant care. This approach is seen as key to enhancing the quality of EOL care. Participants suggested better guidance for caregivers through the healthcare system, the provision of readily available bereavement support, and the clarification of common misconceptions regarding dying-related processes. In addition, as English-speakers participants noted that language barriers could significantly hamper goal-concordant care.

In summary, this chapter reports on key findings pertaining to EOL experiences of English-speaking informal caregivers whose loved one's died by MAiD, PSUD, or natural death with or without palliative care. The findings were organized across four interconnected domains. Overall, participants reported needing detailed information about EOL care and faced internal challenges such role conflict, feelings of guilt, and diverse opinions towards EOL decisions. Participants emphasized how important shared decision-making was regarding care and death location, and participant's role as an intermediary between patient and clinicians. They also highlighted degrees of family involvement in EOL decisions, and support needed from family members other than the primary caregiver, especially for providing home care. The fourth domain (interactions with healthcare) was the most salient, namely how goal-concordant care (i.e., aligning care with patients/caregivers' known goals and values) between participants and the health care team was key in optimizing EOL experiences. Language barriers further challenged coming to terms with goal-concordant care. These findings provide a deeper understanding of English-speaking participants' experiences caring for someone through EOL processes and bereavement so that more tailored supportive interventions can be offered.

Chapter 5: Discussion

This qualitative study explored the experiences of English-speaking informal caregivers in Québec, focusing on personal and contextual aspects of their role in EOL care of a loved one. As the Canadian healthcare system increasingly relies on informal caregivers (often family members) to assist in the unpaid care of its population, it is important to better understand people's informal caregiving experiences including needs and preferences in the context of EOL.

Participants were 16 English-speaking informal caregivers from various Quebec regions who cared for a loved one at EOL until death. Participants were interviewed about their caregiving and bereavement-related experiences. The findings were further organized according to interconnected domains: Internal (i.e., **personal**) caregiver experiences, their **shared experiences** with patient and family members, and caregiver **interactions with the healthcare system**. With regards to personal internal experiences, participants reported several unmet needs related to EOL, balancing various roles in addition to caregiving. They also reported feelings of self-blame/guilt regarding decisions that had to be made along the way. Many reported carrying mixed feelings about EOL-related options.

When sharing their experiences while interacting with the patient and/or family members, participants reported on conversations they shared with them about EOL. Location of death, for instance, was a topic of much discussion as there were divergent views on the topic. Participants also described how, at times, they had to coordinate family involvement and the need for additional physical and psychosocial support, particularly when caring for the dying at home.

Caregiver interactions with the healthcare system emerged as the most significant/intense domain reported by participants. Goal-concordant care - i.e., when care provided by healthcare professionals aligns with patients and caregivers' own goals and values - was underscored as a pivotal component of positive caregiver experiences and seemed to affect the other domains of caregiver experiences. Furthermore, language barriers often posed a challenge in achieving goal-concordant care, particularly for participants in regions where health and social services provided in English tend to be scarce. According to the CHSSN 2022 report, a majority of the 22 community networks they interact with feel underserved when it comes to English language resources (Carter & Pocock, 2022). These include large municipal regional counties (MRC) such as the Outaouais region, the Côte-Nord region, and the northern areas of the Laurentides (Carter & Pocock, 2022). Additional areas of concern are those where English-speaking residents are dispersed across vast distances, notably along the Gaspé Peninsula, in the Abitibi region and in central Québec (Carter & Pocock, 2022). Through some of our own interviews, we were able to pinpoint some of these issues that are further elaborated below according to the aforementioned caregiver experience domains.

Individual (Internal) Caregiver Experiences

The verbatim obtained in this study regarding caregivers' personal and shared EOL experiences resonate with the existing literature, underscoring the often-dual nature of the caregiver's role as both a family member and an advocate, resulting in emotional and physical demands. This multifaceted role can overshadow personal identities as individuals navigate complexities of caregiving (and health care) alongside other social roles such as parental or occupational (Liu, Heffernan, & Tan, 2020). Indeed, the study findings corroborate those by Barnett (2015), on the interplay of caregiving and other roles and their potential contributions to distress. Moreover, the juxtaposition of roles is found to exponentially impact health-related outcomes (e.g., Barnett, 2015; Chumbler et al., 2004; Marks et al., 2008; Stephens et al., 2001; Williams et al., 2008).

The concept of caregiver identity also emerged in the current study as being affected by self and through the dying loved one's dependency on the caregiver. Consistent with Eifert et al. (2015), the evolution of caregiver identity often begins within a familiar context but progressively shifts as the health of the loved one deteriorates. This shift may not be immediately recognized, as caregivers are initially preoccupied with practical aspects of care (Eifert et al., 2015). However, as demands escalate, caregivers may experience role engulfment, where the caring role dominates over their identity, leaving limited time for personal interests or self-care (Eifert et al., 2015). Furthermore, Eifert et al. (2022) discuss the notion that caregiving is often seen as a natural extension of existing roles (i.e. spouse or adult child), which may lead individuals to overlook the label of 'caregiver' preventing them from seeking support resources/respite. Eifert et al. (2022) highlight that caregiver identity acceptance is essential to subsequently access community support effectively. Our findings also reveal that caregivers often carry significant emotional burden, characterized by feelings of guilt and self-blame. These observations are in line with established research where guilt is found to be a significant contributor to caregiver distress, adding to the overall burden of caregiving (Losada et al., 2010; Brodarty, 2007). Duncan et al. (2018) also observed that guilt is prevalent among caregivers who attend to the needs of an individual with dementia, particularly following their institutionalization. The latter relates to our findings that certain participants experienced guilt when placing, at EOL, their loved one into institutional care whether a nursing home or a hospital. Past research also had documented that guilt and self-blame are influenced by caregivers' perceptions of their actions, especially when they contrast with personal beliefs about what constitutes quality caregiving (Losada et al., 2010; Prunty & Foli, 2019). This was demonstrated in the current study as we found that caregivers grappled with guilt when reflecting on end-of-life care decisions, such as postponing MAiD or consenting to (unwanted) medical interventions. Consistent with the work of Gallego-Alberto et al. (2020), our findings also suggest that guilt is not solely a personal cognitive assessment but is also intricately connected to social context and interpersonal relationships. This is further compounded by the complex roles that caregivers occupy, often resulting in neglect of personal needs and other familial responsibilities, contributing to negative self-assessment (Prunty & Foli, 2019). Muro Pérez-Aradros et al. (2023) highlight the relationship between feelings of guilt and psychological distress, suggesting the potential benefits of supportive interventions.

Participants internal experiences were also shaped by their information preferences. Past research reveals that even well intentioned EOL conversations can lead to unintended outcomes such as increased patient and caregiver distress (Sanders et al., 2018; Ernecoff et al., 2021). This echoes our findings that participants expressed divergent information preferences and readiness to engage in EOL conversations. Previous research has emphasized examining how people with serious illnesses, such as advanced cancer, seek information, with varying approaches from actively making decisions about treatment, to sharing decision-making with doctors, or preferring to let doctors to decide (Degner et al., 1997). Loiselle (2019) shows how patients' cancer information-seeking behaviors vary, with some actively searching and others avoiding such information. Studies highlight that patient-centered care relies heavily on the quality of communication between the provider and patient and the personalization of information sharing, which significantly affects the patient's experience, self-management, and health outcomes (Loiselle, 2019; Campbell et al., 2010; Degner et al., 1997). Although this study did not directly assess caregivers’ EOL information preferences, participants spontaneously shared their desires and preferences for better information exchange. They expressed their needs for additional information about their loved one's diagnosis, prognosis, and EOL care plans, and the importance of managing this information to meet their loved ones and their own preferences. Tailored caregiver communication strategies were also found elsewhere to relate to quality of EOL experiences (Sanders et al., 2018; Ernecoff et al., 2021; Shin et al., 2015; Frame et al., 2021; Norton et al., 2019). Caregiver EOL information needs were also related to their perspectives on EOL options such as MAiD and PSUD. While few participants (N=2) expressed concerns that healthcare professionals were potentially expediting patient death for convenience, most viewed MAiD as a compassionate option for individuals with significant suffering. This aligns with the wider Canadian population views, as reflected in a poll by Dying with Dignity Canada (2020), which found that 82% of Canadians out of 3502 support the provision of MAiD, particularly in Québec. Similarly, a qualitative study conducted in Vancouver, BC, interviewing 18 family and friends of patients seeking MAiD revealed unanimous support for MAiD, with participants often transitioning from initial opposition to acceptance upon witnessing their loved one's suffering (Holmes et al., 2018). These findings resonate with our findings, as participants also described experiencing a shift in attitudes as they confronted the realities of their loved one’s terminal illness and its ramifications. Conversely, Trouton et al. (2020) identified that some caregivers interpreted MAiD-related decisions as a reflection of their perceived failure in caregiving leading to feelings of guilt. This sentiment was only echoed by one of the participants in the current study.

In the context of PSUD, research in Europe and the UK has indicated that while many relatives perceive PSUD as contributing to a 'good death,' concerns persist. These include apprehensions about both the patient's and their own well-being, as well as the potential for PSUD to have shortened the patient’s life (Bruinsma et al., 2014). Although a systematic review by Bruinsma et al. (2012) suggests that relatives are generally comfortable with PSUD, it also notes instances of distress associated with its use, a response that was not observed in the current study.

These collective insights highlight the necessity for healthcare providers to engage in sensitive and comprehensive discussions with caregivers regarding MAiD and PSUD. Understanding caregiver apprehensions and supporting them through the decision-making process are critical steps in ensuring that EOL care aligns with the values and needs of both patients and their caregivers. These suggestions will be discussed in more depth in the following sections.

Caregiver-Patient Shared Experiences

In this study, a significant preference among participants was for their loved ones to experience EOL at home, echoing their loved ones' wishes as well as their personal desires. These findings are consistent with previous research indicating a strong preference for home as the location for death. Burge et al. (2015) reported that, among 606 participants, most (74%) favored dying at home. Similarly, broader surveys have suggested that most Canadians would choose to die at home if given the option (CIHI, 2023).

However, it was found that the preference for home death diminishes with individuals opting for palliative care or hospice settings as the severity of illness becomes more intense and in people with lower family support (Funk et al., 2022). Factors that have been independently associated with achieving a preferred home death include having emotional needs met, receiving home visits from nurses and family physicians, and the involvement in palliative care programs (Burge et al., 2015; CIHI, 2023). Yet, although most participants (N=12) reported that their loved ones wanted to die at home, only two were able to realize their wish. This is in line with past research as according to Dying Matters (2017) approximately 70% of people wish to die at home, yet 50% die in hospitals instead (Procter et al., 2019). Herein, participants often faced challenges related to the physical and psychological caregiving demands, medical complexities, and the need for specialized equipment, which posed significant obstacles to a home death. These observations are consistent with previous accounts that the decision to hospitalize individuals at EOL is often contingent on the emotional and physical capacity of caregivers to manage the care required (Procter et al., 2019; Abarshi et al., 2010; Bone et al., 2016; De Korte-Verhoef et al., 2014; Gott et al., 2013; O'Brien, 2010).

These insights underscore the importance of efforts to ensure that formal home-based services are available to assist individuals in managing symptoms and fulfilling their end-of-life location preferences (Funk et al., 2022).

Caregiver-Family Shared Experiences

Study findings delineate the complex interplay among caregiver experiences and family dynamics at EOL, particularly regarding decisions about MAiD and PSUD. Participants reported varied family responses to EOL decisions, ranging from supportive environments to familial conflicts rooted in distinct beliefs and/or religious affiliations. Such family involvement is important as it can influence EOL care decisions and the use of comfort care within hospital settings (Wallace, 2015). The findings align with existing research indicating that caregivers' decisions are deeply affected by their family's views and particularly regarding the potential stigma associated with MAiD (Trouton et al., 2020; Oczkowski et al., 2021; Hales et al., 2019; Holmes et al., 2018; Hashemi et al., 2021; Ho et al., 2021; Laperle et al., 2021). Concerns about external judgment from family, friends, and healthcare providers may lead caregivers to private decision-making, thereby influencing their bereavement support and potentially heightening the risk of complicated grief (Hales et al., 2019; Brown et al., 2020; Hales et al., 2019; Holmes et al., 2018; Hashemi et al., 2021; Ho et al., 2021; Laperle et al., 2021). Findings also underscored the necessity for culturally competent care at EOL, involving the inclusion of family and consideration of cultural preferences related to decision-making (Bullock, 2011; Stein et al., 2009). It is beneficial for healthcare providers to acknowledge and integrate cultural, emotional, and physical dimensions of family dynamics in EOL care to support caregivers effectively and respect patient and family wishes.

Caregiver-Healthcare System Interactions

Goal- and language-concordant communication. Participants interactions with healthcare professionals and the system was intensely discussed by most participants. They reported confronting many challenges including the need to mediate information between their dying loved one and the healthcare team, through the filtering of information to protect their loved ones, for instance. Mulcahy Symmons et al. (2022), acknowledge that caregivers' involvement is critical in information gathering and decision-making and that their preferences, along with the patient's, allow for more concordant EOL experiences. The initiation of conversations about EOL by healthcare professionals is pivotal, as noted in past research, assisting patients and caregivers in decision-making processes (Hauke et al., 2011; Gerber et al., 2020; Luikjx, 2011; Mulcahy Symmons et al., 2022; Piil et al., 2015; Yurk et al., 2002). In the current study eleven participants reported not being satisfied with EOL-related communication, they mainly blamed lack of clarity or its absence.

In addition, an important consideration is the potential mismatch between patient and caregiver preferences for EOL discussions (Mulcahy Symmons et al., 2022; Shin et al., 2015; Yurk et al., 2002). In a systematic review by Mulcahy Symmons et al. (2022) based on 39 studies reviewed , greater attention was acknowledged regarding patient and caregiver knowledge of one another's preferences and to mutual understanding of EOL-related wishes. Based on our findings, many participants were unaware of their loved one's EOL preferences which, in turn, prevented them from fulfilling their wishes. Bloomer et al. (2022) reiterate how formal family meetings are crucial for reaching treatment-related consensus. Others underlined how clear discussions about options and prognosis are very important to caregivers (Mulcahy Symmons et al., 2022; Procter et al., 2019). Campbell et al. (2010)

emphasize the delicate balance required in discussing prognosis realistically while preserving hope, suggesting that understanding patients’ perceptions of their illness and aligning with their understanding can foster trust and facilitate knowledge transfer. Most participants (N=11) herein highlighted the need for more explicit prognostic information from clinicians and better communication when transitioning to EOL. This aligns with Fried's (2022) research, which underscores the importance of communication and the potential adverse effects on caregiver well-being when EOL views conflict.

Misunderstandings also arose about the dying process particularly when clinicians failed to clarify expected unfolding of the process. Drawing on the insights from Dr. Kathryn Mannix, as discussed in her book "With the End in Mind" (2017) and her TEDx Newcastle talk in 2023, the process of dying needs to be demystified. Dying, much like birth, is a process that can be understood and anticipated. She suggests that individuals and their families benefit from being informed about the stages of dying, such as the progression from being less awake to more sleep, and eventually becoming unconscious, along with the changes in breathing patterns that occur towards the EOL. According to Mannix, the trajectory of death is predictable, and having open discussions about it is of paramount importance. She advocates for the significance of such conversations, emphasizing that they provide comfort and support, helping to illuminate a subject that is often surrounded by fear and uncertainty (Mannix, 2023).

Our findings indicate that most participants were unfamiliar with palliative care services offered and EOL options, such as MAiD and PSUD until it was "too late." Caregivers often witnessed their loved ones undergoing aggressive treatment for extended periods, expressing a preference for earlier access to palliative care. This is in line with research that found that the emotional toll of EOL decisions can lead to prolonged feelings of guilt, anxiety, or even post-traumatic stress disorder (Fried, 2022).

The lack of awareness among caregivers regarding palliative care resources aligns with Dionne-Odom et al.'s (2019) findings with a sample of 311 caregivers who represent around 22,669,529 individuals nationally in the U.S., which indicated that over half of caregivers had never heard of palliative care, with many associating it with giving up or imminent death. This highlights a pressing need for interventions to enhance caregiver and public understanding of palliative care services and more specifically the need for health professionals to educate caregivers of palliative care services early in the care trajectory.

The present study also revealed that participants often encountered difficulties due to a lack of clear information and understanding of available resources beyond palliative care. Many participants were unaware of services such as CLSC assistance, bereavement support, or caregiver compensation, reflecting a broader trend of underutilization of support services among family caregivers, as demonstrated in the work by Litwin and Attias-Donfut (2009) (Eifert et al., 2015). This underutilization is further substantiated by Brodaty et al., who found that a significant number (1 in 3) of caregivers for individuals with Alzheimer's were not receiving any support services (Eifert et al., 2015). Most participants were unaware or unable to access support resources, with geographic location emerging as a significant determinant of access to bereavement support. Participants outside of Montréal reported greater difficulty in obtaining grief counseling, a challenge exacerbated by the COVID-19 pandemic (Canadian Grief Alliance Report). The pandemic's impact on bereavement support is notable, with 12 out of 16 participants reporting experiencing the loss of a loved one during this period while facing limited support due to pandemic's constraints.

Likewise, participants from rural areas expressed challenges in accessing bereavement support, highlighting a reliance on remote services such as Zoom, which were less favored by older participants. Language barriers also contributed to the difficulties in accessing therapy in English, which is vital for addressing mental health concerns and reducing social isolation among older community members (Carter & Pocock, 2022). Moreover, the CHSSN report (2022) acknowledges the importance of receiving mental health services in one's preferred language, with a significant portion (81.9% of 3,133) of anglophones in Québec expressing that it is "very important" to them. These findings underscore the need for more research identifying regions in Québec where access to English grief and bereavement support services are limited. There is also a need for healthcare systems to improve the dissemination of information about caregiver support resources including bereavement support. The CHSSN report (2022) states that the CHSSN are working on adapting promotional campaigns and psychosocial support services to be more inclusive and accessible, particularly for anglophone and isolated populations. Language proficiency is an important part of communication and in turn the success of goal-concordant care as stated above. The Quebec Ministry of Health and Social Services emphasized the importance of clear communication to ensure the safety and quality of healthcare services (Carter & Pocock, 2022). They stated that effective communication with English-speaking individuals, is key to ensuring that all information is exchanged accurately, informed consent is secured properly, and confidentiality is upheld consistently (Carter & Pocock, 2022). English-speaking caregivers in this study reported that language barriers hindered clear communication with healthcare providers, aligning with findings from Barlund et al. (2021), who observed that language asymmetry negatively impacts home care and caregiver support.

The role of language in exacerbating stress was particularly noted by six participants who cited it as a compounding factor to communication difficulties with healthcare providers, echoing Sanderson's (2020) observations of the potential for language asymmetry to contribute to severe consequences including inadequate caregiver support. For these participants the reliance on informal interpreters, often family members, was a common but problematic practice due to the risks of misinformation. The issue of the dissemination of incorrect information is highlighted by Silva et al. (2022), who advise against using family members as interpreters.

The remaining 10 participants reported that healthcare teams made accommodations for their language needs, reflecting Sanderson's (2020) findings where caregivers in Québec expressed overall satisfaction with their interactions with clinicians, even when clinicians were not native English speakers. Approximately half of those 10 participants were from Montréal, which has more English health services, suggesting that further research be conducted to understand regional differences in language barriers across Québec specifically in areas with fewer English health services offered (Carter & Pocock, 2022). It would be particularly interesting to look at the differences between caregivers in urban and rural settings as although 9 in 10 English speakers in Quebec live in cities, there are still significant proportions of English-speaking communities living in rural situations in Northern Quebec, Gaspésie & îles-de-la Madeleine, Abitibi-Témiscamingue, Estrie, and Bas-Saint-Laurent (Carter & Pocock, 2022).

Participants also acknowledged other language-related challenges which were in line with Sanderson (2020) and the CHSSN 2022 report, including encountering providers who refused to speak English, hospice staff with inadequate English skills, and the anxiety participants felt when communicating in French, especially when using medical jargon. These issues were compounded by logistical difficulties such as receiving French-only documents and having to travel, sometimes to Ontario, to access English-language bereavement support, with some caregivers also facing discrimination. This is also stated in the CHSSN 2022 report (Carter & Pocock, 2022).

These findings underscore the need for healthcare systems to address language barriers and ensure that professional interpreters are available in palliative care settings. Removing these barriers is essential for reducing caregiver and patient distress and for ensuring that caregivers can effectively support their loved ones without the added burden of language-based miscommunication.

Limitations

The study presents certain limitations that warrant attention. Participants' demographic profiles lacked diversity, predominantly being comprised of Caucasian, cisgender women over 50, thereby excluding other caregiver demographics such as ethnic minorities and indigenous populations, and individuals identifying as 2SLGBTQIA+. This underscores the need for future research specific to these groups to understand the unique challenges they face, as noted by Brodarty and Donkin (2009). Furthermore, varying times since a loved one's death could have introduced recall bias, affecting the accuracy of the experiences reported (Ernecoff et al., 2021).

The qualitative approach used may have been subject to social desirability bias due to the presence of the researcher during interviews potentially influencing participant responses (Ernecoff et al., 2021). Despite efforts to mitigate my own interpretive bias by having my supervisor (CL), the thesis committee members, and other students from the Loiselle Lab review the analysis and interviews, potential social desirability among participants remains a limitation.

Future Directions

Based on the study findings, future research directions on the topic are many. For instance, future research could address training resources for healthcare professionals in EOL communication and the importance of the patient-caregiver-clinician triad on EOL experiences and outcomes. Research could include the systematic testing of promising initiatives to enhance discussions about prognosis, disease trajectories, EOL options, and advance care planning while balancing hope and current realities. Further investigation is also required to determine optimal timing and methods for conducting EOL conversations that align with caregiver/patient goals, needs, preferences, beliefs, and values.

As caregiver goals, preferences, and role can change up to the time of death, the flexibility and adaptability of care plans are essential (Durieux et al., 2022; Fried, 2022; Sanders; 2021; Ernecoff et al., 2021). Future research should consider how to measure and interpret these evolving goals in diverse EOL caregiver samples (Sanders, 2021).
There is also a need to investigate the regional disparities in bereavement services within Québec, particularly where language barriers may impact the provision of support and in rural settings.

Conclusion

This study contributes to the understanding of the experiences of English-speaking caregivers in EOL and bereavement. Participants in this study highlighted how EOL care transcends medical procedures, encapsulating the comprehensive joint experiences of patients, families, their caregivers, and health systems. Participants underscored the need for broader communication that goes beyond treatment objectives focusing more on overall quality of care and quality of life.

Language barriers, particularly for caregivers from minority language groups (English-speaking in Québec), were found to be a significant part of the broader communicative challenges encountered in EOL care. The disconnect between caregivers' needs and the communication offered by healthcare professionals affected their personal experiences, their relationship with the patient, interactions within the family, and their dealings with the healthcare system.

References

Abarshi, E., Echteld, M., Van den Block, L., Donker, G., Deliens, L., & Onwuteaka-Philipsen, B. (2010). Transitions between care settings at the end of life in the netherlands: Results from a nationwide study. *Palliative Medicine*, *24*(2), 166–174. https://doi.org/10.1177/0269216309351381

Act respecting end-of-life care. Gouvernement du Québec. (n.d.). https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/act-respecting-end-of-life-care

Act Respecting French, the Official and Common Language of Québec, and strengthens Bill 101, the French-language charter from 1977 (Bill 96).

Ahn, R., & Aghvami, S. (2020). Innovative care: using 'a day in the life'as a tool to explore opportunities for a tech-enabled home for older Canadians. *Knowledge Management & E-Learning*, *12*(4), 419.

Antonacci, M. (1990). Sudden death: Helping bereaved parents in the picu. *Critical Care Nurse*, *10*(4), 65–70. https://doi.org/10.4037/ccn1990.10.4.65

Aoun, S. M., Breen, L. J., Howting, D. A., Rumbold, B., McNamara, B., & Hegney, D. (2015). Who needs bereavement support? A population based survey of bereavement risk and support need. *PLOS ONE*, *10*(3). https://doi.org/10.1371/journal.pone.0121101

Areia, N. P., Fonseca, G., Major, S., & Relvas, A. P. (2018). Psychological morbidity in family caregivers of people living with terminal cancer: Prevalence and predictors. *Palliative and Supportive Care*, *17*(03), 286–293. https://doi.org/10.1017/s1478951518000044

Asai, M., Fujimori, M., Akizuki, N., Inagaki, M., Matsui, Y., & Uchitomi, Y. (2010). Psychological states and coping strategies after bereavement among the spouses of cancer patients: A qualitative study. *Psycho-Oncology*, *19*(1), 38–45. https://doi.org/10.1002/pon.1444

Banyasz, A., Weiskittle, R., Lorenz, A., Goodman, L., & Wells-Di Gregorio, S. (2017). Bereavement service preferences of surviving family members: Variation among next of kin with depression and complicated grief. *Journal of Palliative Medicine*, *20*(10), 1091–1097. https://doi.org/10.1089/jpm.2016.0235

Barlund, A. S., André, B., Sand, K., & Brenne, A.-T. (2021). A qualitative study of bereaved family caregivers: Feeling of security, facilitators and barriers for rural home care and death for persons with advanced cancer. *BMC Palliative Care*, *20*(1). https://doi.org/10.1186/s12904-020-00705-y

Barnett, A. E. (2015). Adult child caregiver health trajectories and the impact of multiple roles over time. *Research on Aging*, *37*(3), 227–252. https://doi.org/10.1177/0164027514527834

Bauer, A. M., & Alegría, M. (2010). Impact of patient language proficiency and interpreter service use on the quality of psychiatric care: a systematic review. *Psychiatric services (Washington, D.C.)*, *61*(8), 765–773. https://doi.org/10.1176/ps.2010.61.8.765

Bentley, B., & O'Connor, M. (2015). Conducting research interviews with bereaved Family Carers: When do we ask? *Journal of Palliative Medicine, 18*(3), 241-245. doi:10.1089/jpm.2014.0320

Bevans, M., & Sternberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA*, *307*(4). https://doi.org/10.1001/jama.2012.29

Bloomer, M. J., Poon, P., Runacres, F., & Hutchinson, A. M. (2022). Facilitating family needs and support at the end of Life In Hospital: A descriptive study. *Palliative Medicine*, *36*(3), 549–554. https://doi.org/10.1177/02692163211066431

Boivin, A., Gauvin, F.-P., Garnon, G., Gancia, A., Rouly, G., Marcoux, I., & Lehoux, P. (2019). Information needs of francophone health care professionals and the public with regard to medical assistance in dying in Quebec: A qualitative study. *CMAJ Open*, *7*(2). https://doi.org/10.9778/cmajo.20180155

Bone, A. E., Gao, W., Gomes, B., Sleeman, K. E., Maddocks, M., Wright, J., Yi, D., Higginson, I. J., & Evans, C. J. (2016). Factors associated with transition from community settings to hospital as place of death for adults aged 75 and older: A population-based mortality follow-back survey. *Journal of the American Geriatrics Society*, *64*(11), 2210–2217. https://doi.org/10.1111/jgs.14442

Booker, R., & Bruce, A. (2019). Palliative sedation and medical assistance in dying: Distinctly different or simply semantics? *Nursing Inquiry*, *27*(1). https://doi.org/10.1111/nin.12321

Bowen, S. (2001). (rep.). *Language Barriers in Access to Health Care* (pp. 1–103).

Buckle, J. L., Dwyer, S. C., & Jackson, M. (2010). Qualitative bereavement research: Incongruity between the perspectives of participants and research ethics boards. *International Journal of Social Research Methodology, 13*(2), 111-125. doi:10.1080/13645570902767918

Bullock, K. (2011). The influence of culture on end-of-life decision making. *Journal of Social Work in End-Of-Life & Palliative Care*, *7*(1), 83–98. https://doi.org/10.1080/15524256.2011.548048

Burge, F., Lawson, B., Johnston, G., Asada, Y., McIntyre, P. F., & Flowerdew, G. (2015). Preferred and actual location of death: What factors enable a preferred home death? *Journal of Palliative Medicine*, *18*(12), 1054–1059. https://doi.org/10.1089/jpm.2015.0177

Butler, A. E., Hall, H., & Copnell, B. (2018). Bereaved parents' experiences of research participation. *BMC palliative care*, *17*(1), 122. https://doi.org/10.1186/s12904-018-0375-4

Breaking down the key points of Bill 96 | Montreal Gazette. (2022). https://montrealgazette.com/news/local-news/breaking-down-the-key-points-of-bill-96

Breen, L. J., Aoun, S. M., Rumbold, B., McNamara, B., Howting, D. A., & Mancini, V. (2017). Building community capacity in bereavement support: Lessons learnt from bereaved caregivers. *American Journal of Hospice and Palliative Medicine®, 34*(3), 275-281.

Brodaty, H. (2007). Meaning and measurement of caregiver outcomes. *International Psychogeriatrics*, *19*(3), 363-381.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*, *11*(2), 217–228. https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty

Bruinsma, S. M., Brown, J., van der Heide, A., Deliens, L., Anquinet, L., Payne, S. A., ... Rietjens, J. A. (2014). Making sense of continuous sedation in end-of-life care for cancer patients: An interview with bereaved relatives in three European countries. *Supportive Care in Cancer*, *22*(12), 3242–3252. https://doi.org/10.1007/ s00520-014-

Campbell, T. C., Carey, E. C., Jackson, V. A., Saraiya, B., Yang, H. B., Back, A. L., & Arnold, R. M. (2010). Discussing prognosis: balancing hope and realism. *The Cancer Journal*, *16*(5), 461–466. https://doi.org/10.1097/ppo.0b013e3181f30e07

Canadian Virtual Hospice. (2020, October 28). *Grief services falling through cracks of COVID response*. Canadian Grief Alliance . https://www.virtualhospice.ca/Assets/Grief%20services%20falling%20through%20cracks%20of%20COVID%20response_20201028151511.pdf

Carter, J., & Pocock, J. (2022, January). Report on the Health and Social Services Priorities of English-speaking Communities in Quebec. https://chssn.org/wp-content/uploads/2022/10/HC-Priorities-Report-Feb-2022-FINAL.pdf 2344-7

Chi, N. C., & Demiris, G. (2015). A systematic review of telehealth tools and interventions to support family caregivers. *Journal of telemedicine and telecare*, *21*(1), 37-44.

Chumbler, N. R., Rittman, M., Puymbroeck, M. V., Vogel, W. B., & Qnin, H. (2004). The sense of coherence, burden, and depressive symptoms in informal caregivers during the first month after stroke. *International Journal of Geriatric Psychiatry*, *19*(10), 944-953.

Davis, J. D., Hill, B. D., Pillemer, S., Taylor, J., & Tremont, G. (2018). Guilt after placement questionnaire: A new instrument to assess caregiver emotional functioning following nursing home placement. *Aging & Mental Health*, *23*(3), 352–356. https://doi.org/10.1080/13607863.2017.1423029

De Korte-Verhoef, M. C., Pasman, H. R., Schweitzer, B. P., Francke, A. L., Onwuteaka-Philipsen, B. D., & Deliens, L. (2015). How could hospitalisations at the end of life have been avoided? A qualitative retrospective study of the perspectives of General Practitioners, nurses and family carers. *PLOS ONE*, *10*(3). https://doi.org/10.1371/journal.pone.0118971

Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'neil, J., ... & Mueller, B. (1997). Information needs and decisional preferences in women with breast cancer. *Jama*, *277*(18), 1485-1492.

Dillon, E. C. (2016). How home hospice care facilitates patient and family engagement. *Death Studies*, *40*(10), 591–600. https://doi.org/10.1080/07481187.2016.1203377

Dionne-Odom, J. N., Ornstein, K. A., & Kent, E. E. (2019). What do family caregivers know about palliative care? results from a national survey. *Palliative and Supportive Care*, *17*(6), 643–649. https://doi.org/10.1017/s1478951519000154

Downar, J., Fowler, R. A., Halko, R., Huyer, L. D., Hill, A. D., & Gibson, J. L. (2020). Early experience with medical assistance in dying in Ontario, Canada: A cohort study. *Canadian Medical Association Journal*, *192*(8). https://doi.org/10.1503/cmaj.200016

Durieux, B. N., Berrier, A., Catzen, H. Z., Gray, T. F., Lakin, J. R., Cunningham, R., Morris, S. E., Tulsky, J. A., & Sanders, J. J. (2022). "i think that she would have wanted. . .": qualitative interviews with bereaved caregivers reveal complexity in measuring goal-concordant care at the end of life. *Palliative Medicine*, *36*(4), 742–750. https://doi.org/10.1177/02692163221078472

Dying matters. Hospice UK. (2023, December 14). https://www.dyingmatters.org/page/frequently-asked-questions

Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: a literature review. *American Journal of Health Education*, *46*(6), 357–367.

Elliott, B. A., Gessert, C. E., & Peden-McAlpine, C. (2009). Family decision-making in Advanced dementia: Narrative and ethics. *Scandinavian Journal of Caring Sciences*, *23*(2), 251–258. https://doi.org/10.1111/j.1471-6712.2008.00613.x

End-of-life care at the McGill University Health Centre. McGill University Health Centre. (n.d.). https://muhc.ca/patients/end-life-care-mcgill-university-health-centre#:~:text=The%20Act%20respecting%20end%2Dof,prevention%20and%20relief%20of%20suffering.

Ernecoff, N. C., Wessell, K. L., Bennett, A. V., & Hanson, L. C. (2021). Measuring goal-concordant care in palliative care research. *Journal of Pain and Symptom Management*, *62*(3), 314. https://doi.org/10.1016/j.jpainsymman.2021.02.030

Eun, Y., Hong, I.-W., Bruera, E., & Kang, J. H. (2017). Qualitative study on the perceptions of terminally ill cancer patients and their family members regarding end-of-life experiences focusing on palliative sedation. *Journal of Pain and Symptom Management*, *53*(6), 1010–1016. https://doi.org/10.1016/j.jpainsymman.2016.12.353

Fallowfield, L., & Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine. *The Lancet*, *363*(9405), 312–319. https://doi.org/10.1016/s0140-6736(03)15392-5

Flores, G. (2006). Language barriers to health care in the United States. *N Engl J Med*, *355*(3), 229-231.

Frame, A., Grant, J. B., Layard, E., Scholz, B., Law, E., Ranse, K., Mitchell, I., & Chapman, M. (2021). Bereaved caregivers' satisfaction with end-of-life care. *Progress in Palliative Care*, *30*(4), 212–220. https://doi.org/10.1080/09699260.2021.2005756

Funk, L. M., Mackenzie, C. S., Cherba, M., Del Rosario, N., Krawczyk, M., Rounce, A., Stajduhar, K., & Cohen, S. R. (2022). Where would Canadians prefer to die? variation by situational severity, support for family obligations, and age in a national study. *BMC Palliative Care*, *21*(1). https://doi.org/10.1186/s12904-022-01023-1

Fried, T. R. (2022). Giving up on the objective of providing goal-concordant care: advance care planning for improving caregiver outcomes. *Journal of the American Geriatrics Society*, *70*(10), 3006–3011. https://doi.org/10.1111/jgs.18000

Fried, T. R., Bradley, E. H., O'Leary, J. R., & Byers, A. L. (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. *Journal of the American Geriatrics Society*, *53*(1), 59–65. https://doi.org/10.1111/j.1532-5415.2005.53011.x

Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Pérez-Miguel, A., Pedroso-Chaparro, M. D. S., & Márquez-González, M. (2022). "I feel guilty". Exploring guilt-related dynamics in family caregivers of people with dementia. *Clinical Gerontologist*, *45*(5), 1294-1303.

Galletta, A., & Cross, W. E. (2013). *Mastering the semi-structured interview and beyond: From research design to analysis and publication*. New York University Press.

Gerber, K., Hayes, B., & Bryant, C. (2019). Preferences for place of care and place of death: What, how, when and who to ask?. *Progress in Palliative Care*, *27*(2), 64-68.

Gerber, K., Lemmon, C., Williams, S., Watt, J., Panayiotou, A., Batchelor, F., Hayes, B., & Brijnath, B. (2020). 'there for me': A qualitative study of family communication and decision-making in end-of-life care for older people. *Progress in Palliative Care*, *28*(6), 354–361. https://doi.org/10.1080/09699260.2020.1767437

Goldberg, R., Nissim, R., An, E., & Hales, S. (2019). Impact of medical assistance in dying (maid) on Family Caregivers. *BMJ Supportive & Palliative Care*, *11*(1), 107–114. https://doi.org/10.1136/bmjspcare-2018-001686

Gott, M., Frey, R., Robinson, J., Boyd, M., O'Callaghan, A., Richards, N., & Snow, B. (2013). The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers. *Palliative Medicine*, *27*(8), 747–756. https://doi.org/10.1177/0269216312469263

Gouvernement du Canada. (2023, October 4). *Government of Canada*. Canada.ca. https://www.canada.ca/en/health-canada/services/health-services-benefits/palliative-care.html

Government of Canada, D. of J. (2023, June 19). Canada's Medical Assistance in dying (maid) law. Government of Canada, Department of Justice, Electronic Communications. https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html

Government of Canada, S. C. (2022, August 17). *While English and French are still the main languages spoken in Canada, the country's linguistic diversity continues to grow*. The Daily - . https://www150.statcan.gc.ca/n1/daily-quotidien/220817/dq220817a-eng.htm

Grande, G., Rowland, C., Van den Berg, B., & Hanratty, B. (2018). Psychological morbidity and general health among family caregivers during end-of-life cancer care: A retrospective census survey. *Palliative Medicine, 32*(10), 1605-1614. doi:10.1177/0269216318793286

Hales, B. M., Bean, S., Isenberg-Grzeda, E., Ford, B., & Selby, D. (2019). Improving the medical assistance in dying (maid) process: A qualitative study of family caregiver perspectives. *Palliative and Supportive Care*, *17*(5), 590–595. https://doi.org/10.1017/s147895151900004x

Hashemi, N., Amos, E., & Lokuge, B. (2021). The quality of bereavement for caregivers of patients who died by medical assistance in dying at home and the factors impacting their experience: A qualitative study. Journal of Palliative Medicine. Advance online publication. https://doi.org/10.1089/jpm.2020.0654

Hauke, D., Reiter-Theil, S., Hoster, E., Hiddemann, W., & Winkler, E. C. (2011). The role of relatives in decisions concerning life-prolonging treatment in patients with end-stage malignant disorders: Informants, advocates or surrogate decision-makers? *Annals of Oncology*, *22*(12), 2667–2674. https://doi.org/10.1093/annonc/mdr019

Ho, A., Joolaee, S., Jameson, K., & Ng, C. (2021). The seismic shift in end-of-life care: Palliative care challenges in the era of medical assistance in dying. *Journal of Palliative Medicine*, *24*(2), 189–194. https://doi.org/10.1089/jpm.2020.0185

Holmes, S., Wiebe, E., Shaw, J., Nuhn, A., Just, A., & Kelly, M. (2018). Exploring the experience of supporting a loved one through a medically assisted death in Canada. Canadian Family Physician, 64(9), 387–393.

Holtslander, L., Baxter, S., Mills, K., Bocking, S., Dadgostari, T., Duggleby, W., Duncan, V., Hudson, P., Ogunkorode, A., & Peacock, S. (2017). Honoring the voices of bereaved caregivers: A metasummary of qualitative research. *BMC Palliative Care*, *16*(1). https://doi.org/10.1186/s12904-017-0231-y

Informal and family caregiver. Gouvernement du Québec. (n.d.-b). https://www.quebec.ca/en/family-and-support-for-individuals/informal-and-family-caregiver

JACK, B., & O'BRIEN, M. (2009). Dying at home: Community nurses' views on the impact of informal carers on cancer patients' place of death. *European Journal of Cancer Care*, *19*(5), 636–642. https://doi.org/10.1111/j.1365-2354.2009.01103.x

Jackson, J. C., Rhodes, L. A., Inui, T. S., & Buchwald, D. (1997). Hepatitis B among the Khmer. Issues of translation and concepts of illness. *J Gen Intern Med*, 12, 292-298.

Johnson, S. E. (1988). *After a child dies: Counseling bereaved families*. Springer.

Kathryn Mannix. (2023). *What happens as we die? TEDxNewcastle*. Retrieved December 15, 2023, from https://www.youtube.com/watch?v=CZDDByT0Vr0.

Kuzemski, D., Thirlwall, A., Brunton, M., & Brownie, S. (2021). I speak a little arabic: Nursing communication in a cross-cultural context. *Journal of Clinical Nursing*, *31*(1–2), 145–157. https://doi.org/10.1111/jocn.15891

Kissane D. W. (1999). Importance of family-centred care to palliative medicine. *Japanese journal of clinical oncology*, *29*(8), 371–373. https://doi.org/10.1093/jjco/29.8.371

Laperle, P., Achille, M., & Ummel, D. (2021). The relational landscape of bereavement after anticipated death: An interpretive model. *Death Studies*, *46*(10), 2485–2497. https://doi.org/10.1080/07481187.2021.1975177

Laperle, P., Achille, M., & Ummel, D. (2022). To lose a loved one by medical assistance in dying or by natural death with palliative care: A mixed methods comparison of grief experiences. *OMEGA - Journal of Death and Dying*, 003022282210851. https://doi.org/10.1177/00302228221085191

Litwin, H., & Attias-Donfut, C. (2009). The inter-relationship between formal and informal care: a study in France and Israel. *Ageing & Society*, *29*(1), 71-91.

Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International journal of nursing sciences*, *7*(4), 438–445. https://doi.org/10.1016/j.ijnss.2020.07.012

Loiselle, C. G. (2019). Cancer information-seeking preferences linked to distinct patient experiences and differential satisfaction with cancer care. *Patient Education and Counseling, 102*(6), 1187-1193. doi:10.1016/j.pec.2019.01.009

Loiselle, C. G., & Brown, T. L. (2020). Increasing access to psychosocial oncology services means becoming more person-centered and situation-responsive. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, *28*(12), 5601–5603. https://doi.org/10.1007/s00520-020-05659-8

Loiselle, C. G., Howell, D., Nicoll, I., & Fitch, M. (2019). Toward the development of a comprehensive cancer experience measurement framework. *Supportive Care in Cancer, 27*(7), 2579-2589. doi:10.1007/s00520-018-4529-y

Losada, A., Márquez-González, M., Knight, B. G., Yanguas, J., Sayegh, P., & Romero-Moreno, R. (2010). Psychosocial factors and caregivers’ distress: Effects of familism and dysfunctional thoughts. *Aging & Mental Health*, *14*(2), 193-202.

Lowers, J., Scardaville, M., Hughes, S., & Preston, N. J. (2020). Comparison of the experience of caregiving at end of life or in hastened death: A narrative synthesis review. *BMC Palliative Care*, *19*(1). https://doi.org/10.1186/s12904-020-00660-8

LUIJKX, K. G., & SCHOLS, J. M. G. A. (2010). Perceptions of terminally ill patients and family members regarding home and hospice as places of care at the end of life. *European Journal of Cancer Care*, *20*(5), 577–584. https://doi.org/10.1111/j.1365-2354.2010.01228.x

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Malterud, K., Siersma, V., & Guassora, A. D. (2021). Information power: Sample content and size in qualitative studies. *Qualitative Research in Psychology: Expanding Perspectives in Methodology and Design (2nd Ed.).*, 67–81. https://doi.org/10.1037/0000252-004

MANNIX, K. (2019). *With the end in mind: Dying, death and wisdom in an age of denial*. WILLIAM COLLINS.

Marks, N. F., Lambert, J. D., Jun, H., & Song, J. (2008). Psychosocial moderators of the effects of transitioning into filial caregiving on mental and physical health. *Research on Aging*, *30*(3), 358-389.

Martinez, J., & Leland, N. (2015). Language discordance and patient-centered care in occupational therapy: A case study. *OTJR: occupation, participation and health*, *35*(2), 120-128.

Menezes, M. S., & Figueiredo, M. das. (2019). The role of end-of-life palliative sedation: Medical and Ethical Aspects – Review. *Brazilian Journal of Anesthesiology (English Edition)*, *69*(1), 72–77. https://doi.org/10.1016/j.bjane.2018.03.002

Merriam-Webster. (n.d.). *Natural death definition & meaning*. Merriam-Webster. Retrieved October 11, 2022, from https://www.merriam-webster.com/dictionary/natural%20death

Miles, M. S. (1985). Helping adults mourn the death of a child. *Issues in Comprehensive Pediatric Nursing*, *8*(1-6), 219–241. https://doi.org/10.3109/01460868509006363

Minichiello, T. A., Ling, D., & Ucci, D. K. (2007). Breaking bad news: A practical approach for the Hospitalist. *Journal of Hospital Medicine*, *2*(6), 415–421. https://doi.org/10.1002/jhm.271

Mishara, B. L., & Weisstub, D. N. (2013). Premises and evidence in the rhetoric of assisted suicide and euthanasia. *International Journal of Law and Psychiatry, 36*(5-6), 427-435. doi:10.1016/j.ijlp.2013.09.003

Mulcahy Symmons, S., Ryan, K., Aoun, S. M., Selman, L. E., Davies, A. N., Cornally, N., Lombard, J., McQuilllan, R., Guerin, S., O'Leary, N., Connolly, M., Rabbitte, M., Mockler, D., & Foley, G. (2022). Decision-making in palliative care: Patient and family caregiver concordance and discordance—systematic review and narrative synthesis. *BMJ Supportive & Palliative Care*, *13*(4), 374–385. https://doi.org/10.1136/bmjspcare-2022-003525

Muro Pérez-Aradros, C., Navarro-Prados, A. B., Satorres, E., Serra, E., & Meléndez, J. C. (2023). Coping and guilt in informal caregivers: a predictive model based on structural equations. *Psychology, Health & Medicine*, *28*(4), 819-830.

Norton, S. A., Wittink, M. N., Duberstein, P. R., Prigerson, H. G., Stanek, S., & Epstein, R. M. (2019). Family caregiver descriptions of stopping chemotherapy and end-of-life transitions. *Supportive Care in Cancer*, *27*, 669-675.

Oczkowski, S. J., Crawshaw, D. E., Austin, P., Versluis, D., Kalles-Chan, G., Kekewich, M., Curran, D., Miller, P., Kelly, M., Wiebe, E., & Frolic, A. (2021). How can we improve the experiences of patients and families who request medical assistance in dying? A multi-centre qualitative study. *BMC Palliative Care*, *20*(1). https://doi.org/10.1186/s12904-021-00882-4

Piil, K., Juhler, M., Jakobsen, J., & Jarden, M. (2015). Daily life experiences of patients with a high-grade glioma and their caregivers. *Journal of Neuroscience Nursing*, *47*(5), 271–284. https://doi.org/10.1097/jnn.0000000000000158

Pimienta, R. (2023, July 19). *Spotlight on caregiver grief: Initiatives in grief literacy and support*. Council on Palliative Care. https://www.mcgill.ca/council-on-palliative-care/article/spotlight-caregiver-grief-initiatives-grief-literacy-and-support

Pristavec, T., & Luth, E. A. (2020). Informal caregiver burden, benefits, and older adult mortality: A survival analysis. *The Journals of Gerontology: Series B*, *75*(10), 2193-2206.

Procter, S., Ooi, M., Hopkins, C., & Moore, G. (2019). A review of the literature on family decision-making at end of life precipitating hospital admission. *British Journal of Nursing*, *28*(13), 878–884. https://doi.org/10.12968/bjon.2019.28.13.878

Prunty, M. M., & Foli, K. J. (2019). Guilt experienced by caregivers to individuals with dementia: A concept analysis. *International Journal of Older People Nursing*, *14*(2), e12227.

QSR International Pty Ltd. (2020) NVivo (released in March 2020), https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

Quebec end-of-life palliative care policy . Canadian Hospice Palliative Care Association. (n.d.). https://www.chpca.ca/wp-content/uploads/2019/12/Quebec_policy.pdf

Rhodes, M. G., Fletcher, K. E., Blumenfeld-Kouchner, F., & Jacobs, E. A. (2021). Spanish medical interpreters’ management of challenges in end of life discussions. *Patient Education and Counseling*, *104*(8), 1978–1984. https://doi.org/10.1016/j.pec.2021.01.018

Ryan, GW & Bernhard HR (2003). Techniques to identify themes. *Field Methods, 15*, 85–109.

Sanders, J. J., Curtis, J. R., & Tulsky, J. A. (2018). Achieving goal-concordant care: A conceptual model and approach to measuring serious illness communication and its impact. *Journal of Palliative Medicine*, *21*(S2). https://doi.org/10.1089/jpm.2017.0459

Sanderson, D. (2020). Language related difficulties experienced by caregivers of English-speaking seniors in Quebec. *SAGE Open*, *10*(3), 215824402095126. https://doi.org/10.1177/2158244020951261

Scheunemann, L. P., Ernecoff, N. C., Buddadhumaruk, P., Carson, S. S., Hough, C. L., Curtis, J. R., Anderson, W. G., Steingrub, J., Lo, B., Matthay, M., Arnold, R. M., & White, D. B. (2019). Clinician-family communication about patients' values and preferences in Intensive Care Units. *JAMA Internal Medicine*, *179*(5), 676. https://doi.org/10.1001/jamainternmed.2019.0027

Seccareccia, D., Wentlandt, K., Kevork, N., Workentin, K., Blacker, S., Gagliese, L., Grossman, D., & Zimmermann, C. (2015). Communication and quality of care on Palliative Care Units: A qualitative study. *Journal of Palliative Medicine*, *18*(9), 758–764. https://doi.org/10.1089/jpm.2014.0408

Shabnam, J., Timm, H. U., Nielsen, D. S., & Raunkiaer, M. (2022). Palliative Care Utilization among Non-Western migrants in Europe: A systematic review. *Journal of Immigrant and Minority Health*, *24*(1), 237–255. https://doi.org/10.1007/s10903-021-01302-8

Shin, D. W., Cho, J., Kim, S. Y., Chung, I. J., Kim, S. S., Yang, H. K., Ahn, E., Park, B. R., Seo, H., & Park, J.-H. (2015). Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices. *Psycho-Oncology*, *24*(2), 212–219. https://doi.org/10.1002/pon.3631

Silva, M. D., Adelman, R. D., Singh, V., Gupta, R., Moxley, J., Sobota, R. M., Tsai, S., Abel, B. T., & Reid, M. C. (2022). Healthcare provider perspectives regarding use of medical interpreters during end-of-life conversations with limited English proficient patients. *American Journal of Hospice and Palliative Medicine®*, *39*(2), 220–227. https://doi.org/10.1177/10499091211015916

Silva, M. D., Tsai, S., Sobota, R. M., Abel, B. T., Reid, M. C., & Adelman, R. D. (2020). Missed opportunities when communicating with limited English-proficient patients during end-of-life conversations: Insights from Spanish-speaking and Chinese-speaking medical interpreters. *Journal of Pain and Symptom Management*, *59*(3), 694–701. https://doi.org/10.1016/j.jpainsymman.2019.10.019

Smolej, E., Malozewski, M., McKendry, S., Diab, K., Daubert, C., Farnum, A., Orianna, S., Reel, K., & Cameron, J. I. (2022). A qualitative study exploring family caregivers' support needs in the context of medical assistance in dying. *Palliative and Supportive Care*, *21*(2), 254–260. https://doi.org/10.1017/s1478951522000116

Stajduhar, K. I. (2013). Burdens of family caregiving at the end of life. *Clinical & Investigative Medicine*, *36*(3), 121. https://doi.org/10.25011/cim.v36i3.19722

Staniszewska, S., Boardman, F., Gunn, L., Roberts, J., Clay, D., Seers, K., Brett, J., Avital, L., Bullock, I., & O' Flynn, N. (2014). The Warwick Patient Experiences Framework: Patient-based evidence in clinical guidelines. *International Journal for Quality in Health Care*, *26*(2), 151–157. https://doi.org/10.1093/intqhc/mzu003

Stein, G.L., Sherman, P.A. & Bullock, K. (2009). Educating gerontologists for cultural proficiency in endof-life care practice. Educational Gerontology, 35, 1008–1025

Stephens, M. A. P., Townsend, A. L., Martire, L. M., & Druley, J. A. (2001). Balancing parent care with other roles: Interrole conflict of adult daughter caregivers. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *56*(1), P24-P34.

Thangarasa, T., Hales, S., Tong, E., An, E., Selby, D., Isenberg-Grzeda, E., Li, M., Rodin, G., Bean, S., Bell, J. A., & Nissim, R. (2021). A race to the end: Family caregivers' experience of medical assistance in dying (maid)—a qualitative study. *Journal of General Internal Medicine*, *37*(4), 809–815. https://doi.org/10.1007/s11606-021-07012-z

Thorne, S., & Sandelowski, M. (2016). *Interpretive description*. Taylor and Francis.

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The Analytic Challenge in interpretive description. *International Journal of Qualitative Methods*, *3*(1), 1–11. https://doi.org/10.1177/160940690400300101

Tracy SJ (2013). Qualitative research methods: Collecting evidence, crafting analysis, communicating impact. Chichester, UK: Wiley.

Trouton, K., Beuthin, R., Thompson, M., Bruce, A., Lemire-Elmore, C., Zhang, A., & Daudt, H. (2020). Attitudes and expectations regarding bereavement support for patients, family members, and friends: findings from a survey of MAID providers. *BC Med journal,* 62(1)*,* 18–23.

Turcotte, M. (2013). Family Caregiving: What Are the Consequences? *Catalogue No. 75006X.*

Ugalde, A., Gaskin, C. J., Rankin, N. M., Schofield, P., Boltong, A., Aranda, S., . . . Livingston, P. M. (2019). A systematic review of cancer caregiver interventions: Appraising the potential for implementation of evidence into practice. *Psycho-Oncology, 28*(4), 687-701. doi:10.1002/pon.5018

U.S. Department of Health and Human Services. (2022, November). *Providing care and comfort at the end of life*. National Institute on Aging. https://www.nia.nih.gov/health/providing-comfort-end-life

Walbaum, C., Philipp, R., Oechsle, K., Ullrich, A., & Vehling, S. (2023). Existential distress among family caregivers of patients with advanced cancer: A systematic review and meta-analysis. *Psycho-Oncology*.

Wallace, C. L. (2015). Family communication and decision making at the end of life: a literature review. *Palliative and Supportive Care*, *13*(3), 815–825. https://doi.org/10.1017/S1478951514000388

Wasserman, M., Renfrew, M. R., Green, A. R., Lopez, L., Tan-McGrory, A., Brach, C., & Betancourt, J. R. (2014). Identifying and preventing medical errors in patients with limited English proficiency: key findings and tools for the field. *The Journal for Healthcare Quality (JHQ)*, *36*(3), 5-16.

Williams, S. W., Williams, C. S., Zimmerman, S., Munn, J., Dobbs, D., & Sloane, P. D. (2008). Emotional and physical health of informal caregivers of residents at the end of life: The role of social support. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *63*(3), S171-S183.

Woodman, C., Baillie, J., & Sivell, S. (2015). The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence. *BMJ Supportive & Palliative Care*, *6*(4), 418–429. https://doi.org/10.1136/bmjspcare-2014-000794

World Health Organization. (2023). *Palliative care*. World Health Organization. https://www.who.int/health-topics/palliative-care

World Health Organization. (2023). *Non communicable diseases*. World Health Organization. https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases

Yu, Y., Xiao, L., & Chamberlain, D. J. (2021). Perceptions of care in patients from culturally and linguistically diverse background during acute and critical illness: A integrative literature review. *Australian Critical Care*, *34*(5), 486–495. https://doi.org/10.1016/j.aucc.2020.11.004

Yurk, R., Morgan, D., Franey, S., Stebner, J. B., & Lansky, D. (2002). Understanding the continuum of palliative care for patients and their caregivers. *Journal of Pain and Symptom Management*, *24*(5), 459–470. https://doi.org/10.1016/s0885-3924(02)00503-1

2020 poll: Support for medically-assisted dying in Canada. Dying With Dignity Canada. (2022, March 7). https://www.dyingwithdignity.ca/media-center/poll-support-for-medically-assisted-dying-in-canada/

Appendix A

Recruitment Flyer

Réseau de cancérologie Rossy Rossy Cancer Network

Loiselle .lab

McGill | Faculty of Medicine and Health Sciences

DID YOU RECENTLY TAKE CARE OF A LOVED ONE THAT PASSED AWAY?

IS YOUR PREFERED LANGUAGE FOR COMMUNICATION ENGLISH?

WE WOULD REALLY APPRECIATE HEARING FROM YOU!

WE ARE CONDUCTING A STUDY ON FAMILY CAREGIVERS' EXPERIENCES WITH END-OF-LIFE.

If you agree, we will ask you to:

- Sign a consent form
- Take part in a 60-90 minute discussion with a trained interviewer (on Zoom, by phone or in-person)

All Discussions are Strictly Confidential.

PARTICIPATE

Find out more by **following the link**, contacting us by phone, email, or by scanning the QR code below.

☎ 514-398-8977 (Leave a message and we will contact you shortly)

✉ Loiselle.Lab.ccomtl@ssss.gouv.qc.ca

🌐

LINK: https://www.caregiverquebecstudy.com/

This study is led by Dr. Carmen G. Loiselle, Professor at McGill University and Co-Director (Academic, Segal Cancer Centre.

Appendix B

Participant Consent Form

Principal Investigator:
Carmen G. Loiselle, RN, PhD, FCAHS, FCAN
Professor, Department of Oncology and Ingram School of Nursing, McGill University
Senior Researcher, Segal Cancer Centre, Jewish General Hospital, Centre Intégré Universitaire de Santé et de Services Sociaux (CIUSSS)
Phone: 514-398-4163
Email: carmen.g.loiselle@mcgill.ca

Student Investigator:
Justine G. Albert, MSc Student
Division of Experimental Medicine, McGill University
Phone: 514-398-8977
Email: loiselle-research@mcgill.ca

Co-Investigators:
Tyler L. Brown, PhD
Post-doctoral fellow, McGill University

Justin J. Sanders, MD, MSc, FAAHPM
Kappy and Eric M. Flanders Chair of Palliative Care
Director, Palliative Care McGill
Associate Professor, McGill University

Project Title: Palliative and end-of-life experiences among English-speaking informal caregivers in Québec

Sponsor: Rossy Cancer Network

Purpose of the Study:

You are invited to participate in this study because of your experience as an English-speaking caregiver for a significant other (E.g. spouse, partner, parent, child, friend, peer) who died within the past 2-years. More specifically, we are interested in your perceptions of how end-of-life care unfolded.

Take the time to carefully read and understand the information provided below. If you do not understand the information or have questions, please contact Dr. Carmen G. Loiselle or Justine Albert (contact information provided at the bottom of this form). They have the obligation to help you understand all study-related information.

The specific objectives of the study are to explore caregivers' perspectives on end-of-life decision making, patient and caregiver preferences, and communication. The study may provide insights into the experiences of caregivers who may have faced language-related barriers within this context. Findings will help inform the development of more person-centered care approaches that lessen caregiver distress.

Study Procedures:

At the bottom of this consent form you can either click “No, I am not interested” to decline participation or “Yes, I would like to be interviewed” to give consent. If you click “Yes, I would like to be interviewed” you will be contacted in the next few weeks to schedule a date and time for the interview that is most convenient to you. Interviews will either be held in person if you select “I would like to have my interview in person (in Montreal)”, virtually through Zoom if you select “I would like to have my interview virtually”, or by phone call if you select “I would like to have my interview by phone call”.

The interview duration is expected to be between 60 to 90 minutes. The interviews will be audio-recorded and transcribed verbatim. You will also be asked to complete a socio-demographic questionnaire after the interview.

Your consent form and survey responses will be stored securely in Qualtrics, a McGill approved platform for data collection. The link between your name and unique ID will be stored in a secure Qualtrics database and a password-protected file. At all times, only the research team will have access to your information.

Voluntary Participation:

Your participation in this study is completely voluntary, so you can decline to answer any question or withdraw from the study at any time, for any reason. If you decide to withdraw from the study your information will be destroyed. After data collection is completed, data can no longer be withdrawn as during coding the participants will be de-identified. Know that you have the right to ask questions at any time.

Potential Risks:

Efforts will be made to ensure that you are not inconvenienced by your participation in this study. Due to the sensitive nature of the interview topic, you may experience distress or negative emotions while responding to certain questions. You are free to stop the interview at any time then continue the interview at another time or withdraw from the study all together.

Potential Benefits:

Although you may not benefit from participating in this study, it will provide a better understanding of the experiences of English-speaking informal caregivers who experience end-of-life processes. The findings will inform the creation of relevant caregiver supportive resources related to these processes. Participating in this study may be beneficial to you as it can be healing for some people to speak about their experience with a trained listener.

Compensation:

You will not be compensated for your participation in this study.

Confidentiality:

To protect your privacy, all information collected will remain confidential to the extent permitted by law. The Principal Investigator, Dr. Carmen G. Loiselle, remains responsible for preserving the confidentiality of all study data. When analyzing the interview content, you will be assigned a code that will allow a research assistant to transcribe your responses. No identifiable information (e.g., names of people or places, or identifiable situations) will be provide in reporting the data in publications or presentations. Also, your identity will not be divulged to other participants. Direct quotes may be used in publications of findings. However, you will be given a pseudonym in written materials and the information will not be traceable back to you. Overall, the research team will only collect the information needed to meet the scientific goals of the study.

All study information will be kept on a McGill University secure server, including the interview recordings, a subject-ID link, survey data, and transcripts. Only the principal investigator and her research team will have access to the list of participants and any identifiable data. Data (i.e. the consent forms, participant contact information, audio-recordings, and any other study data) will be stored for 7-years following the end of the study by the Principal Investigator, after which all data will be permanently destroyed.

Dissemination of Results:

The results of this study will be disseminated through publications, presentations, and the master's thesis of Justine Albert.

Questions:

For any questions about this form or the study, please contact 514-398-8977 (Leave a message and we will contact you shortly) or email Loiselle.Lab.ccomtl@ssss.gouv.qc.ca. If you have any ethical concerns or complaints about your participation in this study and want to speak with someone not on the research team, please contact the Ethics Officer, FMHS REB/IRB at 514-398-8302 or ilde.lepore@mcgill.ca.

Please type your name below if you have read the above information and consent to participate in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. To ensure the study is being conducted properly, authorized individuals, such as a member of the Research Ethics Board, may have access to your information. A copy of this consent form will be given to you and the researcher will keep a copy.

☐ **I would like to participate in this study**

By typing my full name, I agree to participate in this study.

Typed participant's name:
Date:
Phone Number:
Email:

How would you prefer to be interviewed?
a. Virtually (using Zoom)
b. By Phone
c. In-person (In Montréal)

d. Either virtually, by phone or in-person is fine

☐ **I do <u>not</u> want to participate in this study**

<u>Future studies about the caregiver experience (please choose one):</u>

☐ I give my permission to be contacted for Professor Loiselle's future studies

☐ I do NOT give my permission to be contacted for Professor Loiselle's future studies

Appendix C

Sociodemographic Questionnaire

1) Would describe yourself as the primary caregiver or one of the primary caregivers for your loved-one?
    a. Yes
    b. No
    c. Other (please specify):

2) How old are you? ____68__ years old

3) Which of the following best describes you?
    a. Black
    b. East/Southeast Asian
    c. Indigenous:
        i. First Nations
        ii. Métis
        iii. Inuit
        iv. Prefer to self-describe (please specify): ________
    d. Latino
    e. Middle Eastern
    f. South Asian
    g. White/Caucasian
    h. Another category (Please specify): ________
    i. Prefer not to say

4) Which best describes your current gender identity?
    a. Man
    b. Woman
    c. Gender-diverse
    d. Non-binary

Prefer to self-describe (please write):

5) What are your spiritual/religious beliefs?
    a. Christian
    b. Muslim
    c. Buddhist
    d. Hindu
    e. Sikh
    f. Jewish
    g. Atheist/Agnostic
    h. Other (Please specify)
    i. non

6) What is your marital status?
    a. Never married
    b. Married
    c. Common law marriage
    d. Divorced

  e. Separated
  f. Widowed
  g. Prefer not to say

7) What is the highest level of education you have completed?
  a. Elementary School
  b. High School
  c. Post-Secondary Education
  d. Other (Please specify)

8) What is your annual household income?
  a. Less than $25,000
  b. $25,000 - $49,999
  c. $50,000 - $
  d. $100,000 - $200,000
  e. More than $200,000
  f. Prefer not to say

9) What was your employment status at the time of your loved one's death?
  a. Part-time
  b. Full-time
  c. Unemployed
  d. Other: Please specify ________
  e. Retired

10) Which language do you speak at home? (Check all that apply)
  a. English
  b. French
  c. Spanish
  d. Portuguese
  e. Italian
  f. Mandarin
  g. Japanese
  h. Vietnamese
  i. Hebrew
  j. Arabic
  k. Panjabi
  l. Russian
  m. Other (Please Specify)

11) What was the patient's relationship to you? The patient was my_____
  a. Daughter/Son
  b. Daughter-in-law/Son-in-law
  c. Sister/Brother
  d. Sister-in-law/Brother-in-law
  e. Mother/Father
  f. Grandfather/Grandmother
  g. Great Grandfather/Great Grandmother
  h. Cousin

   i. Aunt/Uncle
   j. Niece/Nephew
   k. Friend
   l. Other (Please specify):

12) How long ago did you **first** have to start helping your loved-one do things that (he/she) was no longer able to do?
   a. Less than 6 months ago
   b. Between 6 and 12 months ago
   c. 1-2 years ago
   d. 3-5 years ago
   e. 6-10 years ago
   f. 11 or more years ago
   g. Other (Please specify):

13) What age was your loved-one when they died? _______ years old

14) What was the deceased loved-one's underlying medical condition?
   a. Cancer (Please specify cancer type)
   b. Cardiovascular (Please specify)
   c. Respiratory (Please specify)
   d. Neurological (Please specify)
   e. Multiple comorbidities (Please specify)
   f. Other

15) What was the deceased love one's location of death?
   a. Hospital
   b. Hospice
   c. Home
   d. Long-term care facility

16) Was the above location the desired setting of death?
   a. Yes
   b. No

17) Who was in the room at the patients time of death? _____________

Use the following information for questions 18 and 19.

Palliative care is patient-centred coordinated care that aims to relieve suffering and improve quality of life for patients and their families at all stages of the illness. Palliative care focuses on a holistic approach to treat the impact that an illness has on patients and their families and is often provided in addition to clinical care that focuses on treating the illness itself.

Types of Palliative care services:

- Physician and nursing services to assess and manage the progression of the illness. This includes providing pain and symptom management to improve comfort and quality of life
- Personal support services (e.g., homemaking)
- Psychological, social services, spiritual and bereavement support
- Other services, such as physiotherapy, caregiver support, pharmacy

18) Based on the definition and the examples of palliative care services above, did your loved one receive palliative care?
    a. Yes
    b. No
    c. Somewhat (Please specify):

19) If applicable, how satisfied were you with the quality of palliative care that your loved one received?
    a. Very Unsatisfied
    b. Unsatisfied
    c. Neutral
    d. Satisfied
    e. Very Satisfied

20) What type of treatment did the patient receive?
    a. Medical Assistance in Dying (MAiD)
        1. To what extent are you in favor of MAiD?
            a. Very much in favor
            b. In favor
            c. Neither in favor nor against it
            d. Against it
            e. Very much against it
        2. To what extent do you think your family, friends, and colleagues are in favor of MAiD?
            a. Very much in favor
            b. In favor
            c. Neither in favor nor against it
            d. Against it
            e. Very much against it
            f. Have no idea
        3. To what extent do you think society of Quebec is in favor of MAiD?
            a. Very much in favor
            b. In favor
            c. Neither in favor nor against it
            d. Against it
            e. Very much against it
            f. Have no idea

    b. Palliative Sedation

1. To what extent are you in favor of PSUD?
    a. Very much in favor
    b. In favor
    c. Neither in favor nor against it
    d. Against it
    e. Very much against it
2. To what extent do you think your family, friends, and colleagues are in favor of PSUD?
    a. Very much in favor
    b. In favor
    c. Neither in favor nor against it
    d. Against it
    e. Very much against it
    f. Have no idea
3. To what extent do you think society of Quebec is in favor of PSUD?
    a. Very much in favor
    b. In favor
    c. Neither in favor nor against it
    d. Against it
    e. Very much against it
    f. Have no idea

c. Natural Death
d. Neither
e. I prefer not to say

21) Time elapsed since death (in months) __________

22) What was your involvement during the deceased loved-one's end-of-life? Frequency of visits:

a. Less than 1 day a week
b. 1-2 days a week
c. 3-4 days a week
d. 5-6 days a week
e. 7 days a week

23) Duration of visits:
a. Less than 30 minutes
b. Between 30-60 minutes
c. Between 1 and 3 hours
d. Between 3 and 5 hours
e. More than 5 hours

24) Where did you live in relation to your loved one while caring for them?
a. Same neighbourhood
b. Same town/city
c. Same region
d. Same province

    e. Other (Please specify):

25) Did you move to live closer to your loved one during the time leading up to their death?
    a. Yes
    b. No
    c. Somewhat (Please specify):

Appendix D

Qualitative Interview Guide

NOTE:

Palliative Sedation Until Death (PSUD) is the use of sedative medications to induce a state of decreased consciousness to alleviate intractable symptoms at the end-of-life in a way that is ethical and accepted by the patient, family, and healthcare provider.

Medical Assistance in Dying (MAiD) is when a provider administers medications or substances to a patient, at the patient's request in order to relieve their suffering and hasten death.

Natural Death (ND) is when the death occurs from natural causes such as age or disease without any external forces.

Thank you again for agreeing to participate in this interview. We really appreciate your help in this important research topic.

Segment 1: Overall narrative

1) Can you tell me about your significant other (name)? How would you describe him/her, and can you talk about the nature of your relationship?
2) Can you share your story and start anywhere you'd like about your significant other's death.

Additional Prompts:

- Can you briefly describe the context in which your significant other died? How/where did the death take place?
    i. Where did your significant other die?
    ii. What did you witness in terms of symptom management such as pain, other discomfort, nausea? Were you told by the healthcare team of any changes in how they were providing care? (e.g., increased pain medication?

Segment 2: Questions of greater specificity

Before Death Event

MAIN QUESTION: Please provide an overview of the events that took place leading up to the death of your significant other.

Additional Prompts:

1) Were you part of end-of-life decisions involving your significant other?
2) What was your experience with the healthcare team in the end-of-life decision making?
3) What **support** did the healthcare team provide you at this time?

During Death Event

MAIN QUESTIONS:

Were you present during the death of your significant other? How did you experience this moment? What was your emotional experience?

Additional Prompts:

4) What location did the death take place in? Were you satisfied with the location? Was it the preferred location?
5) How did you react when your significant other died? Did you experience any particular emotions?
6) Have these reactions evolved or changed between the death and today? if so, how have they evolved/changed? If not, in your opinion, why didn't they change?
7) How would you describe the relationship you had with your significant other at the moment of his/her death?
8) How would you describe the relationship you have with him/her today; with his/her memory; with his/her image?
9) Does the relationship you have with his/her memory differ from the relationship you had with him/her while he/she was still alive? How so?

After Death Event

MAIN QUESTION: What has your experience been since the death of your significant other and into bereavement?

Additional Prompts:

10) How has the event of the passing of your significant other impacted your daily life? If not, in your opinion, how come nothing has changed?
11) Did you seek **supports**? At what point?
    a. Do you receive, or did you receive **support** during bereavement? If so, can you tell me a little bit more about how you feel towards this **support**? If not, can you tell me why you did not receive **support**?
12) How do you feel/believe that those close to you/around you/in your environment perceive you while you are(were) in the process of grieving?
13) How do you feel about these perceptions?

14) What is your general opinion about the way your significant other died? (Particularly if MAiD or PSUD)
15) In your opinion, what do people around you think about the way your significant other died? Do their views affect you? If yes, how? If not, why?

Segment 3: Revisiting the Opening Narrative for important theoretical connections and closure.

16) Is there anything else you would like to share regarding your experience? Something you feel we forgot to talk about.
17) Are you aware of Quebec's Bill 96? Does this Bill pose any concerns for you? Do you feel this Bill would have affected the experience of your significant other's death?

Thank participant for their time!

Appendix E

Distress Protocol

Step 1. **Monitor Signs**	Monitor for early signs of discomfort and distress, for example. • Diverting the conversation • Body Language (Take into consideration the cultural norms of the participant) Monitoring for early signs of distress may be more difficult when conducting research study procedures at a distance (by telephone or virtually) • Some signs, however, may still be apparent, such as facial expressions or tactics to divert the conversation.
Step 2. **Participant Appears Uncomfortable**	If participant appears to exhibit signs of discomfort: • Ascertain how the participant is feeling. • Remind the participant that they may refuse to answer any question, but still remain in the research study and/or take a break. If the participant continues to appear uncomfortable even after refusing to answer questions and/or taking a break: • As indicated in the REB approved research study protocol/proposal and information form, remind the participant to consult the listing of appropriate resources, following the completion of the research study procedures. These resources are ether listed in the information form or separate document that had been previously given the participant. Ask the participant if they wish the resource list to be resent.
Step 3. **Participant Exhibits Signs of Distress**	If the participant exhibits or expresses signs of distress, either verbally or behaviourally (e.g. uncontrolled crying , shaking, emotional outbursts etc.) • Ask participant. o If they wish to stop the recording o Depending upon the response, ask if the participant wishes to withdraw from the research study.

	- If the participant wishes to withdraw from the research study, access the participant's mental status. - As specified in the REB approved research study protocol/ proposal and information and consent form , either: - Suggest that you can refer the participant to an appropriate resource for help (e.g., the employee assistance program)
Step 4. Participant Exhibits signs of Extreme Distress	If the participant exhibits extreme level of distress, they may cause imminent harm to themselves or other, immediate action is required: - Take measures to obtain necessary and urgent intervention to protect the participant, immediately. Advise the health care institution so that it can initiate specific reporting procedures.

Appendix F

Language Skills Classification Based on LinkedIn Language Levels

- **Basic knowledge** - you are using just basic vocabulary and can hold simple and short conversations, for example at a small talk level. You are aware of the most important grammatical rules. *(no need to include it in your CV/LinkedIn profile)*
- **Good/conversational** level means you understand a basic framework of everyday conversation, both active and passive. However, for more in-depth conversation, you lack some vocabulary, as well as grammatical rules.
- **Very good/fluent** level means you can effortlessly speak fluently on a wide variety of topics. You are making some small mistakes, but on the other hand, you are reading demanding texts or watching foreign-language films. Being at this stage of language proficiency, your vocabulary is very distinctive and includes colloquial expressions and typical idioms.
- **Native language = mother tongue** is a language you have grown up with, so if you have not grown up with it, you must not call it your mother/native tongue.

(Kujawiak, M. (2021, February 7). *Best way to classify and list language skills on your resume and linkedin profile*. LinkedIn. https://www.linkedin.com/pulse/best-way-classify-list-language-skills-your-resume-profile-kujawiak/)