A palliative approach to care for people living with dementia: exploring perspectives from health and social care providers working in long-term care

by

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A thesis

presented to the University of Waterloo

in fulfilment of the

thesis requirement for the degree of

Master of Science

in

Public Health and Health Systems

Waterloo, Ontario, Canada, 2021

AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

ABSTRACT

Background: The number of Canadians living with dementia is rising as our population ages and is projected to reach 1.4 million people by 2031. Dementia is a terminal neurogenerative condition and is a major contributing factor to the transition into long-term care settings for many. Currently, most persons living in long-term care settings in Canada have a form of cognitive impairment or diagnosis of dementia, and most persons with dementia will die in a long-term care setting. A palliative approach to care that is appropriate for persons living with dementia in these settings is essential both now and in the future. However, research demonstrates that in Canada, end-of-life care and experiences are suboptimal for persons with dementia. Further, most Canadian long-term care homes do not have a formalized palliative care program and the integration of a palliative approach remains uncommon. There is growing international and Canadian interest in palliative approaches to care for persons with dementia and in long-term care settings, but there is a lack of Canadian research that provides a dementia-specific focus on palliative approaches in long-term care settings.

Objectives: This qualitative descriptive study explored the perspectives of health and social care providers working in long-term care settings on the use and optimal delivery of a palliative approach to care for people with dementia living in long-term care settings. Specifically, this study examined the following research questions: (1) How is a palliative approach to care being used with persons with dementia who live in long-term care; (2) What are the perceptions of health and social care providers roles in supporting a palliative approach to care with persons with dementia; and (3) What contributes to an optimal palliative approach to care for people with dementia in long-term care?

Methods: Individual semi-structured interviews were conducted with 20 health and social care providers who work with persons living with dementia in long-term care in Southern Ontario, Canada. Data were transcribed, anonymized, and analyzed using conventional content analysis in NVivo 12.

Results: Of the 20 participants interviewed, their occupations included: activation manager, assistant director of care, dietary aide, nurse practitioner, occupational therapist, personal support worker, physician, recreational therapist, registered nurse, registered practical nurse, social worker, spiritual care provider. Five categories were identified through conventional content analysis: (1) Need for a Shared Understanding of a Palliative Approach to Care for Persons with Dementia; (2) Discussions About Goals of Care and the Future; (3) "End-of-Life Care" and Psychosocial, Grief, and Bereavement Support; (4) Need for Collaboration and Relationship-Based Care; and (5) Recommendations for an Optimal Palliative Approach to Care for Persons with Dementia.

Conclusion: Study results highlight that while palliative principles are recognized as important for persons with dementia, and components of a palliative approach are being used, there is a clear need for a shared understanding amongst staff, as well as further integration of a palliative approach to dementia care in long-term care. Study participants also identified recommendations for an optimal palliative approach for persons with dementia in long-term care, including: (1) Clarify roles in supporting a palliative approach for persons with dementia; (2) Support staff with grief and bereavement; (3) Improve staffing and funding models to be appropriate for the care needs of persons with dementia; (4) Timely and consistent care planning discussions; (5) Improve the availability and quality of end-of-life resources; (6) Improve the built environment to better suit the needs of persons with dementia; and (7) Provide continuous and accessible care provider education. Results from this study indicate there is a need to support health and social care providers to enable a higher quality integrated palliative approach to care for persons with dementia and in the emotional labour of caring for persons with dementia who are dying.

ACKNOWLEDGEMENTS

The University of Waterloo, where I completed this degree, is situated on the Haldimand Tract, land that was promised to the Haudenosaunee of the Six Nations of the Grand River, and is within the territory of the Neutral, Anishinaabe, and Haudenosaunee peoples. This thesis was written on the traditional territories of the Erie, Neutral, Huron-Wendat, Haudenosaunee and Mississaugas.

Thank you to my supervisor, Dr. Carrie McAiney. I am so grateful for your mentorship, support, and kindness. I have learned so much from you throughout the course of my MSc, and I am excited and honoured to continue into my PhD under your supervision.

Thank you to my committee members, Dr. Sharon Kaasalainen and Dr. George Heckman. I am deeply appreciative of you both for sharing your expertise with me, and for your guidance and support.

A sincere thank you to all the health and social care providers who participated in this study. I am so grateful for the time you all took to share your stories, perspectives, and recommendations with me. You all do incredible, challenging work. Your passion and dedication to improving the care experiences and quality of life and death for persons living with dementia and their families are remarkable.

To Dan, thank you for always being supportive and having kind words to say.

To the amazing women in my research group, thank you for being amazing colleagues and friends. Emma, your comments on my work will delight and haunt me forever. I appreciate you.

To my friends and colleagues in my cohort, you are all such an inspiring group of people. I greatly look forward to following all your continued journeys in your education and careers. I am saddened that our time together on campus was cut short, but I am thankful for the strong bonds we formed as a cohort very quickly.

To Carolyn, Raisa, and Tierney, I don’t have the words to thank you all for your unconditional love and support. I am in constant awe of you all.

To Dayle, thank you for listening to me talk in circles, endlessly, while I tried to figure out what I was doing, almost every single day. Also, for putting on horror movies so I would not come downstairs and be forced to work in solitude – I appreciate the innovation.

Finally, to my loved ones, thank you for all the support. My family and friends, you all know who you are. I appreciate many of you for listening to me talk about palliative approaches to care for persons with dementia in long-term care in every social situation I was involved in for the last year. (and for also listening for the next 4 ish years).

DEDICATION

In loving memory of my grandpa, Robert Hicks.

For everyone living with dementia.

For everyone who has had, and will have, a loved one pass away with/from dementia.

For everyone that provides compassionate and dedicated care to those living in long-term care.

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CHAPTER 1: Introduction

This chapter provides a brief high-level overview of the need to improve palliative care in Canada for persons with dementia living in long-term care. A palliative approach to care is introduced, including a description of the associated terminology and components within this approach to care. This chapter closes with the purpose of this study.

1.1 Brief Rationale

Due to world population aging, an increasing number of people will have progressive, life-limiting conditions, such as dementia [1,2]. Approximately 50 million people are currently living with dementia worldwide [3], and this number is expected to triple over the next 30 years to reach 150 million [4]. In Canada, currently over half a million people are living with dementia [5], and in the next 15 years, Canada is expected to face a doubling in its population of people with dementia [6]. Dementia is a neurodegenerative and terminal condition that results in cognitive and functional decline due to the progressive deterioration [3,7]. Since dementia is a terminal condition, palliative care is appropriate for persons with dementia [8], and is increasingly being considered best practice [9]. Dementia is associated with complex health and social care needs and high morbidity rates in the later stages [10]. Therefore, persons with dementia can have a range of care needs, often including long-term care services [10]. In North America, most persons with dementia die in long-term care [11], making this a palliative care setting. Thus, it is very concerning that research demonstrates that persons living with dementia in long-term care have poor end-of-life experiences and receive suboptimal palliative care [12].

1.2 Palliative Approach to Care and Associated Terminology

The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care [1], developed in 2015 through a collaboration between the Canadian Hospice Palliative Care Association and the End-of-Life Care Coalition of Canada, outlines strategies and best practices to integrate a palliative approach to care into all health care settings and services. In this Framework, a palliative approach to care is defined as care that meets a person's and their family's physical, psychosocial, and spiritual needs throughout the stages of a progressive illness [1]. In this approach, palliative care services are not exclusive to the end stages of an illness, but instead are offered early on, potentially alongside curative treatments or diagnosis, to provide a support system to help both the person and their family - the former to have a high quality of life and death with reduced suffering, and the latter to help cope during the individual's illness and in their bereavement [1,13]. Therefore, a palliative approach to care situates palliative care less as a distinct service offered at end-of-life when treatment is no longer effective, and instead as an approach to care that can improve quality of life for the duration of an illness trajectory, ideally beginning as early as a diagnosis [1,14].

Currently, there is variation in the understanding and use of the terms 'palliative care' and a 'palliative approach to care' within experienced professional groups, and a subsequent misconception among the public [2,3,12]. In addition, the terms 'hospice palliative care', 'death with dignity', 'comfort care', and 'end-of-life care' are increasingly being used to reflect the dying process and the related care provided [12]. Definitions and distinctions between terms are unclear both in literature and in practice; 'end-of-life care' has been defined as relating to individuals who are likely to die within the next 12 weeks, including those whose death is considered imminent [12]. Further, the care provided to those whose death is considered imminent has been termed by some as "last hours and days of care" [16]. 'Hospice palliative care' has been defined as care that aims to improve quality of life and relieve suffering [1]. While hospice palliative care and end-of-life care have similar aims, palliative care can and should be offered earlier than at someone's end-of-life [17]. However, for many people, including health and social care providers, the word 'palliative' is associated with end of life, in particular the last weeks or days of life [1,12]. This misconception places the notion that palliative care relates only to the very end-of-life and therefore as only relevant to the advanced phase of an illness [12]. This research is focused on a palliative approach to care as defined by The Way Forward National Framework [1], as this approach encompasses end-of-life care and hospice palliative care. Within this thesis, when reporting on literature where authors have used various terms for a palliative approach to care, the terminology used by the authors will be used instead of 'palliative approach to care'.

1.3 Components of a Palliative Approach to Care

A palliative approach to care is a relatively newer way of conceptualizing palliative care in Canada. Previously, palliative care in Canada was mainly associated with specialized end-of-life care and most often only offered to people dying from a malignant disease such as cancer [14,18]. Since the Canadian population is aging and the prevalence of persons living with dementia in Canada is increasing, the Canadian government has recognized the need for palliative approaches to care across all health sectors [14]. The Way Forward Framework [1] outlines a ‘roadmap’ to help Canada achieve an integrated palliative approach to care across all care settings. In this Framework, a palliative approach to care is specifically outlined as incorporating palliative care principles, namely open communication regarding illness prognosis and trajectory, advance care planning, psychosocial and spiritual support, pain and symptom management, and regular opportunities to review goals of care, with the usual care someone receives across care settings throughout their illness [1,13]. Therefore, a palliative approach that is person-centered and involves both physical care and psychosocial and spiritual support to lessen the individual’s spiritual and emotional suffering and enhance their quality of life and well-being throughout the trajectory of their illness [1,15], and includes:

Communication about an individual’s prognosis and illness trajectory. In a palliative approach, it is recognized that most people want to be informed about their illness and diagnosis, and their prognosis, and should have opportunities to discuss their illness prognosis and trajectory with their health and social care providers [1]. These conversations should include discussing any changes that the individual may have to make in their lives as their illness progresses [1].

Advance care planning. The process of advance care planning involves ongoing formalized discussions about an individual’s wishes, preferences, and values for their future care to help ensure that they receive care consistent with their wishes, preferences, and values in case that individual loses their capacity for decision making, which can be relevant in the case of people living with dementia or cognitive decline [19,20]. Every province and territory in Canada have different laws that govern advance care planning. In Ontario, consent for treatment can only be acquired at the time a decision is needed, therefore, advance care plans are not consent for future care [21]. Within a palliative approach, the aim is to begin these conversations early on, and often include establishing a substitute decision-maker or a power of attorney. The roles of a substitute or proxy decision maker also have different titles across provinces and territories in Canada. In Ontario, a substitute decision maker is a person, or persons, chosen by the individual or appointed by the state and is entitled by law to act on behalf of best interests in terms of healthcare decisions if the individual loses their capacity for decision-making [1,21]. The role of the substitute decision-maker is only to provide consent for the treatment when a person is considered incapable of doing so, not to express wishes or values for future or end-of-life care on behalf of the individual [21,22].

Psychosocial and spiritual support. In a palliative approach to care, psychosocial and spiritual support is offered both for the individual and their family. This support is provided if individuals or family members are struggling with any issues or losses related to the illness [1]. Spirituality is a construct that is inclusive of how an individual makes meaning and organizes their sense of self, including their set of values, beliefs, and relationships [14]. Someone's spirituality can take many forms, for example, through connecting to nature, music, religion, rituals, or storytelling. For many people, being part of a community of faith is a significant part of their identity and spirituality [1,14].

Pain and symptom management. Pain and other distressing symptoms can cause discomfort and be due to the illness itself, the treatments for the illness, and/or the process of aging. Pain and symptom management throughout an illness is a crucial component of a palliative approach to care to reduce discomfort and enhance quality of life and well-being [1].

Reviewing goals of care. As an individual progresses through their illness, they would be provided regular opportunities to review their goals of care and have their care adjusted to reflect the changes in their goals in a palliative approach to care [1].

Referrals to expert hospice palliative care services. If required, individuals with complex and intensive care needs at their end-of-life can be referred to expert hospice palliative care services to help support their care [1,14]. Evidence suggests that only a small amount of people will require hospice palliative care provided by expert palliative care teams [1,14].

However, everyone who has dementia can benefit from palliative care services. With an integrated palliative approach to care, most Canadians can receive these palliative services from their current providers (e.g., physicians, registered nurses, nurse practitioners, social workers, personal support workers, occupational therapists, and spiritual care persons) across the settings they receive care, such as primary care, home care, and long-term care [1,14]. In turn, this means that non-specialist health and social care providers need to have competencies in palliative care, although with access to experts and specialists for referral and consultation if needed [14]. Therefore, an integrated palliative approach to care is not only accessible across care settings, but also cost-effective as it can limit visits to the emergency department and hospital [1,14].

Overall, the aims of a palliative approach to care are to maintain and improve quality of life [8]. A palliative approach to care is appropriate and needed for persons with dementia [14]. Although, persons in Canada living with dementia in long-term care receive suboptimal palliative care and a majority of long-term care homes do not have any formalized palliative program [23]. As such, it is imperative that a shift is made to offer an integrated palliative approach to care in the long-term care sector that is appropriate to support the complexities of living with and dying with or from dementia [1,14].

1.4 Study Purpose

While there is growing interest in examining palliative approaches for persons with dementia and palliative approaches in long-term care, there is a dearth of research from a Canadian perspective. Notably, there is a lack of Canadian research providing a dementia-specific focus *in* long-term care settings. Using qualitative inquiry, this thesis aims to contribute to the body of knowledge in Canada by examining the current use and optimal delivery of a palliative approach to care for people living with dementia in long-term care from the perspective of health and social care providers. The recommendations for an optimal palliative approach to care for persons with dementia as identified by health and social care providers in this research can help to improve quality of care, life, and death for persons with dementia in long-term care.

CHAPTER 2: Background and Key Topics

This chapter provides an overview of the current state of palliative care in Canada and a description of dementia and long-term care settings in Canada, highlighting Ontario in particular. It also provides a look into the unmet palliative needs of persons with dementia and the applicability of palliative approaches in long-term care settings for those living with dementia. The chapter closes by detailing the current literature concerning the role of health and social care providers and relevant barriers to the provision of a palliative approach for persons with dementia.

2.1 Overview of Palliative Care in Canada: The Current State and Increasing Need

At present, Canada does not have a national palliative care program. Therefore, there are differences in the care available in each province and territory [14]. Since there are 14 different systems for providing care (i.e., 13 provincial and territorial jurisdictions, and the Federal Government is responsible for mandated populations) there is significant variation and inequality in the palliative care services provided in Canada [14]. Subsequently, there are variations in strategies, policies, and funding models that affect the accessibility and delivery of palliative care across Canada [2]. Some health regions or institutions determine their own criteria for who qualifies for palliative care, resulting in further variation [2]. Evidence shows that few Canadians receive palliative care outside of hospitals, and more than 80% of the cases when people in hospitals received palliative care, their hospital stay was unplanned, or they were admitted through the emergency department [2]. In long-term care, data from the Canadian Institute for Health Information demonstrates that only 6% of persons living in long-term care have a record of receiving palliative care in their last year of life [2].

The delivery of palliative care in Canada has improved in recent years, however numerous reports have demonstrated ongoing gaps in quality and accessibility of palliative care [14]. In Ontario specifically, while there has been an increase in the proportion of people who receive palliative care, from 61.4% in 2017-18 compared to 58.6% in 2014-15, nearly half of those people only received palliative care in the final month of their lives [24]. This use of palliative care services is not congruent with a palliative approach to care which can begin as early as a diagnosis of a progressive, life-limiting illness is received [24]. In Canada, we have recognized the need to shift our thinking that palliative care is only a priority at end-of-life when curative treatments have stopped and see palliative care as pertinent for all life-limiting, progressive illnesses [14]. Further, the distinction between an integrated palliative approach to care that can be delivered by a range of providers across illness trajectories and the expert hospice palliative care services provided by specialized teams for those with complex needs at end-of-life needs to be elucidated [14].

Recognizing the gaps in access and quality of palliative care, in 2018 Canada released a Framework on Palliative Care [14]. Overall, there are four priorities outlined in the Framework for action: (1) Training and education for health and social care providers and caregivers, (2) Raising awareness of measures to support palliative care providers and care partners, (3) Improved research and data collection on palliative care and, (4) Measures to facilitate equitable access to palliative care [14]. Although there is evidence of an unmet need for palliative care in Canada across all disease groups, one of the most notable gaps in access to palliative care is for those living with dementia and cognitive decline [2,9,25,26].

Canada released its first national dementia strategy, A Dementia Strategy for Canada: Together We Aspire [27], in June 2019. The Canadian strategy identifies principles and objectives to help guide all groups of people, from the government to individuals, working with those who have dementia and on dementia-related initiatives. The three national objectives are to: (1) prevent dementia, (2) advance therapies and find a cure, and (3) enhance the quality of life of persons with dementia and care partners [27]. The Dementia Strategy [27] states that persons living with dementia in Canada are less likely to be referred to palliative care teams, are prescribed less palliative care medications, and experience increased difficulties in accessing end-of-life care than persons diagnosed with other life-limiting, progressive conditions. The following section will define dementia, describe the living and dying process associated with dementia, and provide evidence of the applicability of a palliative approach to dementia care.

2.2 Dementia

Dementia refers to a group of conditions with a common set of symptoms resulting from disorders affecting the brain that cause deterioration in cognitive function (i.e., the ability to process thought) and behavioural abilities [28]. Dementia is characterized by an indeterminate trajectory of cognitive and functional decline that is distinct from other diseases. Dementia affects memory, thinking, comprehension, orientation, learning capacity, language, visual perception, self-management, problem-solving, and judgement [29]. Consciousness is not affected, although cognitive impairment is frequently accompanied and sometimes preceded by a decline in emotional control, motivation, or social behaviour [28,29]. There are various forms of dementia, including Alzheimer's disease, vascular dementia, Lewy-Body dementia, and frontotemporal dementia. Alzheimer's disease accounts for 60-80% of cases, making it the most common form of dementia [29]. While the different types of dementia all have different physical and cognitive effects, all forms of dementia are progressive and involve physical and mental deterioration [30]. Evidence shows that persons with dementia have an average of two to eight additional chronic conditions and require a complex combination of health and social care [30,31,32].

The signs and symptoms associated with dementia are often categorized in three stages of progression; these stages typically correlate to the level of health and social care support required. There are varying opinions on which signs and symptoms are in the early- versus middle-stages of progression, however there is consensus on the symptoms of late-stage. The range of experiences of those living with dementia is vast, where health can be relatively simple to support, or complex with severe physical and emotional distress [12,33]. People with dementia will require a variety of care and support throughout each stage, with most people needing full-time assistance with their activities of daily living in the final stage [34]. Activities of daily living include personal hygiene, continence management, toileting, dressing, ambulating, and feeding [28]. For family and care partners, caring for a loved one with dementia can involve a lot of emotional, physical, and financial responsibility [34]. Dementia is often thought of as a trajectory, although that trajectory is an individual journey. The type of dementia, environmental factors, and the individual's circumstances before becoming ill, dementia will affect each person differently. Similarly, the rate of symptom progression also varies [28].

Early-stage symptoms of dementia may not be widely apparent and often overlooked, as the onset is gradual [28,29]. Generally, early-stage symptoms include memory problems, difficulties coming up with the right word or name, becoming lost in familiar places, confusion with time or place, challenges in planning or problem solving, visual-perceptual difficulties, changes in mood or emotion, and difficulty completing familiar tasks [28,29]. As dementia progresses to the middle-stage, the signs and symptoms are more pronounced and generally include worsening memory with difficulties remembering personal history and information, needing help with personal care, incontinence, declined wayfinding abilities, changes in sleep patterns, and demonstrating personality and behavioural changes [28,29]. In the middle-stage, the individual living with dementia can often still participate in daily activities with assistance [28]. The late stage of dementia is often also referred to as the final stage, where symptoms are severe. In this stage, persons with dementia lose the ability to respond to their environment and eventually to control their movement, including walking, sitting, and swallowing [28]. An individual may still use words although, there is increased difficulty in communicating. As memory and cognitive function continue to decline, significant personality changes may take place. In late-stage dementia, there will be a severe impact on most aspects of a person's life, and they will likely need full-time support with daily living and personal care for activities of daily living [28]. Additional symptoms of late-stage dementia may include altered perception (visual and auditory hallucinations) and heightened vulnerability to infections (e.g., pneumonia) [28].

2.2.1 End-of-life: dying with or from dementia

Since there is currently no cure for dementia, and since a cure is not foreseen soon, many people will die with or from dementia [8]. Thus, a palliative approach is appropriate and has been shown to be beneficial for the quality of care, life, and death of persons living with dementia [8]. While dementia is a terminal illness, dementia may not be the cause of death, as it interacts with other conditions and can complicate or exacerbate these other conditions [35]. Living with multimorbidity is associated with an increased risk of mortality, disability, and poor quality of life [36]; the relationship of having dementia with other long-term health conditions can result in a cumulation of increased risk leading to adverse outcomes [37]. Therefore, although someone may die with dementia, they may die from another illness or because of multimorbidity [38,39]. Many people with advanced dementia die from malnutrition and dehydration, heart conditions, or infections such as pneumonia [40]. Fever, eating and intake difficulties, inability to swallow, complications of bowel and bladder incontinence, decubitus ulcers, and distressing symptoms such as shortness of breath and pain are common in end-of-life for people with dementia [33,41]. A very recent narrative review conducted by Eisenmann et al. (2020) [25] reported that in nursing homes, persons with dementia most commonly experience mobility restrictions, pain, and sleeping disorder in their last 12 months of life.

The end-of-life stage is inconsistently defined for people with dementia as the transition from living to actively dying can be a lengthy trajectory [9]. Consequently, due to the unpredictability of progressive deterioration, evidence shows that identifying when an individual with dementia is dying is difficult and not always recognized by health and social care providers [12,33,38]. Although there have been frameworks developed to guide identification of stages in dementia, they can be limited in effectiveness by the common influence of multimorbidity [12]. Similarly, there is a lack of a reliable prognostication tool for those with dementia [34], and while dementia-specific indicators exist to help health and social care providers identify deteriorating health and dying, given the variability in trajectories, aging-related care needs, and high prevalence of multimorbidity, these indicators are only guide [12,34].

The World Health Organization advances that everyone with a progressive, life-limiting condition has the right to palliative care [4]. Since dementia is an incurable life-limiting illness, palliative and end-of-life care for people with dementia are considered best practices [8,9,42]. The National Institute for Health and Clinical Excellence guidelines recommend that persons living with dementia receive palliative care from the time of their diagnosis until their end-of-life [43]. How health and social care providers view dementia, such as a chronic condition, as a disability, or as a terminal illness, impacts how it is understood and subsequently treated [44]. To effectively provide a palliative approach to care for persons with dementia and their families and care partners, dementia must be recognized as a terminal illness [45]. However, dementia is often not seen as a cause of death, a terminal illness or as a palliative approach issue [12,26], and the skills and capacity of the health and social care provider workforce, supports, and services are often challenged by the complex care needs of persons with dementia [10].

In Canada, few people living with dementia receive palliative care or a palliative approach to care despite having an all-cause mortality rate 4.4 times higher than other older adults [46]. Currently, it is not a standard of care to include a palliative care team when someone is diagnosed with dementia [34], despite numerous reports indicating that a lack of access to palliative care services and an integrated palliative approach to care results in poor quality of life and death for those with dementia [1,16,26]. There is an abundance of evidence demonstrating that pain is underdiagnosed and untreated in people with dementia [9,39,47]. Further, evidence demonstrates that people living with dementia experience increased hospitalization, invasive treatments such as tube feeding and restraints [48,49], undermanagement of multimorbidity, and increased agitation and other symptoms [14]. The spiritual needs of people with dementia are also frequently overlooked, and evidence demonstrates that health and social care providers often lack confidence in assessing and meeting spiritual needs of those with dementia [39]. Encouragingly, there is a growing recognition that the palliative care provided to people with dementia needs to improve. That is, the care persons with dementia receive should be equal to that received by individuals with other life-limiting, terminal conditions such as cancer, where there is already a defined palliative approach with end-of-life planning and support [50]. Elsenmann et al. (2020) [51] importantly note that palliative care provided to people with cancer is not simply transferrable to people with dementia. There is a need to adapt palliative care knowledge and expertise to the particular and individualized care needs of persons with dementia [52]. Notably to address the progressive nature and plan for the advanced complexities that present toward and at the end-of-life [12].

2.2.2 A palliative approach to dementia care

A palliative approach to care for persons with dementia aims to enhance quality of life, dignity, and comfort, through providing an individualized care plan including meaningful engagement, appropriate physical and psychosocial care, and treatment of symptoms associated with dementia [53]. The care provided should be grounded in a personalized approach to meet the needs, values, and preferences of the individual and their family. The main philosophy of care for persons with dementia in recent years has been one that is person-centered [54]. Kitwood (1997) [54] introduced the concept of person-centred care for those living with dementia, discussing the importance of recognizing their personhood in addition to the symptoms of the disease. Person-centred care emphasizes the perspectives and rights of the individual living with dementia and as previously discussed, is a guiding principle within a palliative approach to care [12,50]. Thus, the philosophy of a palliative approach to dementia care emphasizes ongoing relationships with the individual and their family, focuses on more than just the disease, and integrates the concept of personhood [49].

A palliative approach acknowledges that dementia is a life-limiting, terminal illness, and if this approach to care is adopted early, may help to promote advance care planning, and offer guidance in addressing complex ethical dilemmas [6,32]. As a palliative approach can provide for a more individualized response to complex physical needs in advanced dementia, inappropriate interventions, and transfers within and across the care system can be avoided [6,32]. Family members are often substitute or proxy decision makers for those living with dementia, meaning they must make care decisions about the administration of antibiotics and treatments, hydration, and nutrition [26]. A palliative approach to dementia care offers support to families in their role as decision-makers, and advance care planning improves communication and shared decision-making which can reduce unnecessary and unwanted hospitalizations, the use of burdensome interventions such as parenteral hydration and tube feeding [55,56]. A systematic review conducted by Petriwskyj and colleagues (2014) [57] found that both staff and families report difficulties sharing and obtaining information from each other, that families are not consistently supported and are given little information to guide them in end-of-life decision-making. Many families were dissatisfied particularly in terms of lack of communication with inconsistent and infrequent contact from staff [57]. Further, evidence indicates that people want to die in their 'home', which includes long-term care homes, rather than be hospitalized, and people would prefer to receive palliative care from their regular health and social care providers [46]. This is imperative for long-term care homes as care providers know residents well and have developed personal relationships with them. Additionally, a palliative approach offers support to families in coping with the high burden of care and grief often associated with caring for a loved one with dementia, and into the bereavement stages [1,56].

Recognizing the need for improved palliative care for persons with dementia, the European Association for Palliative Care (2013) produced a white paper defining optimal palliative care for those with dementia via a five-round Delphi study [8]. van der Steen and colleagues [8] outline 11 domains and 57 recommendations. The 11 domains include: (1) applicability of palliative care; (2) person-centered care, communication and shared decision making; (3) setting goals and advance care planning; (4) continuity of care; (5) prognostication and recognition of dying; (6) avoiding unnecessary, burdensome and aggressive treatment; (7) providing comfort and optimal symptom management; (8) psychosocial and spiritual support; (9) family involvement and care; (10) health and social care team education; and (11) societal and ethical concerns. As most dementias are progressive and life-limiting, ultimately leading to death, a palliative approach is applicable and recommended [8]. Further, the goals of dementia care change over time and can include life prolongation treatment as these may relieve burdensome symptoms, with the focus on maintaining function, optimizing quality of life, and maximizing comfort, and are therefore compatible with a palliative approach [8]. Additionally, the paper purposes that while not all individuals with dementia require specialists palliative care designed to manage complexities, a palliative approach to care is required as a baseline for those with dementia [8]. The paper puts forth that a palliative approach to care refers to all treatment and care in dementia care, including treatment of multimorbidity and behavioural and psychological symptoms and should be provided through the philosophy of person-centered care [8].

A systematic review conducted by Senderovich and Retnasothie (2019) [34] aimed to understand the impact of palliative care in dementia management. The review was undertaken because the function of palliative care in for persons with dementia is not well explained, therefore the review specifically sought to elucidate and evaluate the literature to support or refute the benefits of palliative care in dementia management. The review indicates that in studies that evaluated palliative care consultation either shows benefit or is suggested to have benefit if implemented [34]. This is important as the review highlighted that in terms of standards of care provided to people living with dementia, there is suboptimal management of symptoms and gaps in provider education. Symptoms in advanced dementia are comparable in severity to terminal cancer, however the same emphasis on the necessity of palliative care and pain and symptom management has yet to be paralleled in the population of persons with dementia [34. Further, this review found that discussions of goals of care and end-of-life care involving palliative care consultations showed greater concordance between family decision-makers and providers, receiving palliative care reduced emergency room visits, and palliative care consultation reduced medication and pharmacy costs [34]. The review acknowledged that palliative care should be implemented at earlier stages of the dementia trajectory to use healthcare resources more efficiently and to improve the experiences of people living with dementia, and their families [34].

Evidence suggests persons with dementia living in long-term care receive suboptimal palliative care [9]. While there is this growing recognition in recent years of the need for a palliative approach to care for persons with dementia, efforts to promote quality of living and dying for persons with dementia in long-term care have been neglected, especially for those with advanced dementia [58]. Further, the evidence from a Canadian perspective pertaining to palliative approaches to dementia care in long-term care settings is lacking. A scoping review by Antonacci and colleagues (2020) [59] identified the gaps in hospice and palliative care research in North America. The review concluded that overall, there were limited studies exclusively addressing gaps in palliative care, to which they reported could be due to a lack of focus in the area of palliative care on what improvements are needed. Further, the review found that there is a need for more research into those with advanced dementia, and in terms of access to care, the review identified a lack of hospice, palliative and end-of-life research in long-term care homes. Finally, there were gaps in study designs, notably among those gaps is a lack of qualitative research on various topics in hospice, end-of-life, and palliative research, including quality of care [59].

A palliative approach to care that is dementia-specific is needed to promote quality of life [8], importantly, in long-term care where a vast majority of residents have dementia, and where most people with dementia die [11]. The following section further elucidates the high proportions of those living with dementia in long-term care and the current state of a palliative approach in the long-term care setting.

2.3 Long-Term Care

The role long-term care plays in the continuum of care for persons with dementia is increasingly important. Also known as nursing homes, long-term care homes provide continuous on-site health and social care through nursing services and personal care assistance for chronic conditions for predominately older adults who can no longer live independently [60]. In Canada, it is anticipated that the demand for long-term care will increase 10-fold by 2038 [61]. In Ontario, there are 627 long-term care beds and currently 40,000 people on the waitlist [62], and the average time of placement into a long-term care home is 152 days [63]. Long-term care staff primarily consist of nursing staff and unregulated care providers such as personal support workers, recreational therapists, dietary care aides, and chaplains or spiritual support persons [64]. In addition to nursing staff, other regulated care providers include physicians, nurse practitioners, pharmacists, dietitians, occupational therapists, and physiotherapists, however, these professionals are not regularly onsite [64]. Personal support workers are the largest population of employees in the long-term care sector and have the most time providing care spent with residents [65]. The second largest population of care provider's working in long-term care are registered nurses [65]. Long-term care homes in Canada are increasingly caring for persons who are dying. Most Canadians living in long-term care settings are highly vulnerable and are often frail, have some form of cognitive impairment, and have at least one chronic condition [1,66]. Since people living in long-term care settings are highly vulnerable, death is common [1]. Annual mortality rates of residents in long-term care homes range from 27 to 52.3% [11,67]. Further, the average length of stay until death for residents are becoming shorter [11,68], and most people stay in long-term care until their end of life [2]. The average expected lifespan is now less than two years post-admission [69]. Therefore, long-term care homes are increasingly becoming more hospice-like, necessitating a palliative approach to care [68]. Currently, in Canada, around one-third of people with dementia under the age of 80 live in long-term care home [70]. The proportion increases to 42% for those 80 years and older [70]. In Ontario, people living in long-term care are 84 years old on average, and 90% of long-term care residents have a form of cognitive impairment, two out of three residents have a diagnosis of Alzheimer's disease or another dementia [60,66]. A population-based retrospective cohort study explored the five-year risk of admission to long-term care home and death for older adults with a new diagnosis of dementia in Ontario [71]. Among those with dementia, 48.4% had been admitted to a long-term care home at some point during the five years. At the end of the 5 years, 55.1% of the cohort had died with more than half of those people being admitted to long-term care before death [71]. Further, it’s estimated that 70% of people with dementia in Ontario will eventually require long-term care services [63].

With a large proportion of Canadians, and Ontarians as notably relevant to the current study context, with dementia being cared for and dying in long-term care, providing a palliative approach appropriate for persons with dementia care in this setting is necessary. Since many people transition to long-term care due to their dementia, a resident with dementia should receive a palliative approach that starts upon admission [72]. However, despite the growing awareness of the importance of implementing a palliative approach in long-term care settings, evidence suggests that the capacity of the long-term care sector in Canada has kept pace with the needs of the increasingly complex aging population [68]. As evidenced by many reports, the implementation of a palliative approach remains uncommon in Canada’s long-term care sector [14,50].

As previously discussed, the provision of palliative care in Canada is directed by policies at various levels of government and within different jurisdictions and organizations. Evidence suggests there are discrepancies among palliative care guidelines in high-level guiding documents which could result in inadequate provision of palliative care [73]. Hill and colleagues (2019) [74] conducted a study aiming to examine the extent and consistency of high-level palliative care guiding documents in long-term care across five Canadian provinces (Alberta, Ontario, Saskatchewan, Manitoba, and Quebec). Overall, twenty-five documents were included that are palliative care guidelines and policy statements. The authors state that this small number of guiding documents is a concern, as it indicates the lack of policy documents that exist across Canada on palliative care [74]. Further, this review concluded that long-term care specific documents were absent, and that in all the documents that do exist lack consistency on palliative topics. Long-term care was cited in most documents (92%) however, the role of long-term care in palliative care was discussed minimally. Hill and colleagues [74] further state that since they found no foundational documents in place, the likelihood of long-term care homes having any sort of palliative program is not likely. It was concluded that there is a clear need to develop, implement, and evaluate a palliative model in Canadian long-term care settings to improve both quality of living and dying for residents and to ensure families are supported [74].

Concurrently, a relatively recent report from the Canadian Institute for Health Information (2018) [2] shows that most residents living in long-term care with less than 6 months to live did not have a record of palliative care in 2016-2017. Although, this report states that even though few people received formal palliative care in the last year of their life, it is possible that many did received care that was palliative in nature [2]. Therefore, it is imperative to gather an understanding of the actual use of a palliative approach in this care setting to work toward ensuring long-term care homes have the capacity to deliver a high-quality palliative approach to care, particularly that is appropriate for those with the complexities of living with dementia.

2.3.1 The role of health and social care providers in supporting a palliative approach for persons with dementia

Health and social care providers working in long-term care settings have a critical role in addressing palliative care needs for persons with dementia [75]. However, the training of Canadian health and social care providers in palliative care has been described as inadequate, particularly in terms of palliative care for people living with dementia, and available data suggest that a limited number of care providers specialize in providing palliative care [2,14]. Both international and Canadian literature supports that there is a need to improve the knowledge base of health and social care providers working in long-term care settings regarding palliative and end-of-life care for persons with dementia. Chen et al. (2017) [76] conducted a descriptive, cross-sectional study to examine the attitudes toward and knowledge of palliative care for persons with advanced dementia amongst nursing staff in nursing homes in Taiwan. The study's findings demonstrate that overall, there is a need to provide nurses and nursing assistants with more education regarding palliative care for persons with advanced dementia [76]. Notably, it was found that those who had greater work experience and had received palliative and hospice training had more knowledge of palliative care, and those who had received dementia care training had higher levels of positive attitudes towards palliative care [76]. Similarly, results from a Canadian study conducted by Kaasalainen et al. (2017) [77] regarding the occupation specific palliative care educational needs of persons working in long-term care homes found that support staff (recreation, dietician aids, office staff, laundry, kitchen, and housekeeping) rated their comfort level of working with persons who are dying significantly lower than personal support workers and nurses. Although, study results suggest that both support workers and personal support workers have higher education needs [77]. While this study was set in long-term care settings and involved a wide range of staff, the focus was not dementia specific [77].

Some work has been done in Canadian long-term care homes to examine health and social care providers experiences of palliative and end-of-life care for persons with dementia. McCleary et al. (2018) [50] engaged 77 staff members and 19 relatives of persons with dementia living at four long-term care homes in four Canadian provinces. The research team sought to explore family and long-term care staff experiences of end-of-life and end-of-life care for persons living with dementia in long-term care [50]. The study sample of long-term care staff included health care aides, registered nurses, registered practical nurses, licensed practical nurses, allied health professionals, housekeeping, dietary staff, managers, and support staff [50]. The study found that longstanding relationships resulting in care providers knowing the person with dementia intimately was essential to provide person-centered end-of-life care [50]. Further, health care aides were identified as needing more involvement in end-of-life care planning discussions, as they have a vast knowledge of residents with dementia. The study further concluded that long-term care staff felt uncomfortable answering family members questions about end-of-life, and that bereavement support needs among staff were unmet [50]. This study supports that additional training, both in palliative care for people living with dementia, as well as education on the competencies of other professions, is needed to improve palliative care for people with dementia and interdisciplinary collaboration.

Perceptions of long-term care staff's roles in providing a palliative approach for persons with dementia is a relatively new topic of study in Canada. A Canadian study conducted by Kaasalainen et al., (2007) [78] sought to explore 34 nurses' perceptions around providing palliative care for persons living with dementia in long-term care. This study involved registered nurses, registered practical nurses, personal support workers, and one nurse practitioner [78]. Employing a qualitative descriptive design, the study reported barriers and facilitators to providing palliative care to those with dementia that nurses faced in managing competing demands in an environment with limited resources [78]. Study results found that participants held a goal of facilitating a "good death" for residents both with and without dementia [78]. However, providing a good death was dependent on meeting the care needs of the individual with dementia, their families, and the nurses themselves, which participants identified feeling challenged to meet [78]. Participants reported that they largely neglected caring for themselves as caring for the residents and their families took precedent [78]. Challenges to providing palliative care that were inherent to the health care system and long-term care environment were identified, including: a lack of privacy in dementia care units, understaffing, inconsistent staff, lack of continuity of care, and a need for stronger communication between care providers [78]. Having positive relationships built on mutual trust with physicians was identified as a facilitator of providing effective palliative care [78]. Study participants identified that providing education about palliative care to families was often a nursing responsibility and therefore, the nurses felt they needed more education and support to help families in making care decisions [78]. Kaasalainen et al. [78] discussed how participants did not appear to label dementia itself as a palliative care diagnosis and thus, it is likely persons dying with dementia died without palliative care measures.

Evidence suggests that for health and social care providers to take on the intricacies of a palliative approach for persons with dementia, for example, taking on the role of facilitating end-of-life care and decision-making discussions requires a subjective perception of the role with a collective team understanding of who takes on that role [49]. Subsequently, research indicates a need to understand the division of roles and responsibilities amongst health and social care provider's in providing a palliative approach to care [4] and to examine how long-term care staff work within dynamics of interdisciplinary teams [49]. Further research is needed to better understand the perceptions of health and social care providers roles in supporting a palliative approach for persons with dementia in long-term care in Canada.

2.4 Identified Barriers and Challenges to the Provision of a Palliative Approach for Persons with Dementia

The lack of implementation of a palliative approach to care for people with dementia and in long-term care is frequently discussed in relation to barriers that exist at numerous levels [79]. As previously discussed, providing palliative care for people with dementia has unique challenges due to the high prevalence of multimorbidity and unique progression and presentation of symptoms resulting in the need of complex health and social care [49]. This is coupled with the eventual loss of ability to self-direct their care, make decisions and express themselves verbally, resulting in the loss of ability to communicate their wishes and preferences as well as experiences of pain or discomfort [49,80]. Thus, health and social care professionals must rely on their observations, the knowledge of the family, and potential information from advanced care planning to provide palliative and end-of-life care [81]. As also noted previously, there are difficulties with prognostication [79,82], limited access to palliative care programs and specialists, administrative and policy issues [60], lack of communication between providers and families, and a lack of workforce education and skills regarding a palliative approach to care for those with dementia, particularly around needs for pain and symptom management [83,84].

In the context of long-term care, the philosophy of care has often been referred to as a medical or biomedical approach to care making the focus of care on medical management and extending life [85]. It has been reported that Ontario's long-term care homes are shifting away from a medical model of care that is associated with fixed tasks and scheduling to a more person-centered and flexible approach to care [63]. However, studies conducted in Ontario long-term care homes have reported otherwise [49,55].

A scoping review conducted by Erel, Marcus, and Dekeyser (2017) [79] on the barriers to palliative care for advanced dementia found that care providers' personal characteristics such as gender, age, past experiences, attitudes, and personal preferences regarding palliative and end-of-life care, religious beliefs, and cultural backgrounds all impact the provision of palliative and end-of-life care. In line with the medical or biomedical model of long-term care, the review reports that many physicians tend to focus on acute, potentially reversible illnesses instead of acknowledging the terminal aspects of a resident's conditions [79].

Similarly, international and Canadian studies have indicated that long-term care staff have varied understandings of a palliative approach to care, what it encompasses, and when it is applied [50,85]. Evidence suggests that care providers beyond physicians in long-term care also situate palliative care within the biomedical model whereby the provision of palliative care is to be used when curative options are exhausted, as the focus is on maintaining life [49,85]. A qualitative study conducted by Sutherland, Wiersma, and Vangel (2019) [49] in Ontario aimed to examine the barriers and facilitators to long-term care staff's involvement in end-of-life decision making for people with advanced dementia. The study interviewed registered nurses, registered practical nurses, and personal support workers' and four interconnected barriers were identified: (1) the predominance of a biomedical model of care where care is centered around physical care and treatment with little discussion about the preferences and values of the person with dementia; (2) a varied understanding of a palliative approach to care with most participants viewing palliative care as care provided only when curative treatment is exhausted; (3) challenging relationships with families; and (4) discomfort discussing death [49]. The study reported that instead of adopting a palliative approach to care that is integrated into everyday practice, participants understood palliative care as a set of physical tasks to be completed [49]. Sutherland et al. [49] state that further research is needed to elucidate how long-term care staff work within power dynamics of interdisciplinary teams regarding facilitating end-of-life care decision-making discussions. This study contributes to the findings in the literature that demonstrate that the policies and practices in long-term care are not tailored to a palliative approach to dementia care [49]. Like other studies conducted in Canada regarding palliative care for people with dementia in long-term care from staffs' perspectives, study participants only included members of the nursing team [49].

Literature also suggests that there is staff role ambiguity regarding end-of-life and a palliative approach for people with dementia, and that a hierarchical work culture exists within long-term care homes [60]. Not only does a medical or biomedical approach to care emphasize a task-oriented approach to care, but also emphasizes a role-differentiated approach to work [86]. The provision of a palliative approach to care in long-term care is reported to be challenged by which occupations on the care team are listened to regarding care planning and decision making [87]. The previously mentioned study conducted by Sutherland and colleagues (2019) [49] found that although there was a team approach to providing care, the hierarchy in long-term care may have prevented genuine interprofessional collaboration. Hierarchical work environments have resulted in care providers (e.g., personal support workers, registered practical nurses, registered nurses) working separately and making their status known through distinctions of how they're titled, and the work expected from them in their roles [88]. These hierarchies are often classified according to the level of education required for each staffing group. This means that personal support workers are at the bottom of the hierarchy as they have the least amount of education [49]. Even though personal support workers provide an invaluable component of care to those with dementia and have intimate knowledge of residents which is instrumental to providing a person-centered, palliative approach to care [50], their perspectives may not be prioritized or included in care conferences and discussions with other care providers regarding residents' goals of care [89]. Knowing the individual with dementia has been cited as necessary in providing compassion, comfort, and pain assessment and management when the individual with dementia could no longer communicate in words [50]. However, physicians and registered nurses have been considered to have clinical, objective knowledge that has placed them in higher status than personal support workers performing bodily work. Interestingly, registered nurses have also been subjugated by these hierarchies [90] and have been reported to lack confidence and understanding in their role in end-of-life decision-making and discussions [91].

Further, organizational factors within long-term care have a significant impact on the quality of care provided to residents [92]. Factors such as poorly developed teamwork and leadership [60], a lack of interprofessional collaboration [50,60], resource shortages [79], crowded rooms [93], and challenging workload demands with low ratios of care providers to residents [55] all directly contribute to the quality of care toward and at end-of-life [92]. Evidence shows that inadequate staffing and time constraints in long-term care have been found to lead to poor uptake of advance care planning [94]. A very recent Canadian study conducted by Cloutier et al. (2021) [95] that is part of a larger project across four provinces titled *Seniors – Adding Life to Years*, aimed to understand the impacts of a palliative approach to care-quality improvement initiative on health and social care providers in long-term care, notably, registered nurses, licensed practical nurses, and health care aides. Specifically, this paper aimed to evaluate the challenges with embedding a palliative approach to care from the perspective of 80 care providers, predominantly in nursing and health care aide roles [95]. Thematic analysis revealed that while long-term care front-line workers are committed to providing a high-quality palliative approach to care, they are challenged by "longstanding conditions in long-term care" [95]. These longstanding conditions in long-term care were identified as staffing shortages and perceived lack of time for providing compassionate care [95]. Further, participants varied in their views on what a palliative approach to care is, and subsequently, when it should be applied. Cloutier et al. [95] posited that an integrated palliative approach to care depends on front-line workers access to adequate resources for education and training, as well as supportive leadership.

2.5 Summary

Dementia is a neurodegenerative, terminal condition for which palliative care is considered best practice [3,7]. However, evidence suggests that persons with dementia living in long-term care in Canada receive inadequate palliative and end-of-life care [14,27]. This results in poor end-of-life experiences with increased pain and other symptoms, hospitalizations, burdensome treatments, and unmet psychosocial and spiritual care needs [27]. Further, given the growing prevalence of persons living with dementia in Canada who will need care in long-term care settings, there is a clear and urgent need for the integration of palliative approaches suitable for this population in these settings [15,27]. However, since the release of The Way Forward National Framework [1] and the Framework on Palliative Care [14], there has been limited evidence on if a palliative approach to care has been adopted in long-term care settings. That is, there is a lack of information on access to palliative care in terms of services available, the experiences of those providing and receiving care, and evidence on the quality and extent of implementation of a palliative approach in long-term care in Canada [2]. There is even less evidence investigating a palliative approach for persons with dementia in this setting. Further, research continue to identify a range of barriers and challenges to the provision of optimal palliative care for persons with dementia [49,92,96], both living in long-term care and other settings. Notably to the current thesis, these barriers in long-term care have been studied for more than a decade, yet the ways to overcome many of them are not clear or have not been widely realized in practice yet [79].

To enhance quality of life and dying for people with dementia in long-term care, there needs to be a nuanced understanding of the current use of a palliative approach with this population and an understanding of health and social care providers perceptions of roles in supporting a palliative approach. Of interest is elucidating health and social care providers' perspectives on an optimal palliative approach for persons with dementia in long-term care homes. Together, this information can support directions for future practice and research within Canada. As a result of time spent caring for persons with dementia in long-term care settings, health and social care providers know their residents with dementia intimately [50]. Perspectives from health and social care providers provide crucial context for building the evidence base on the processes and considerations for palliative approaches to care for those with dementia [48]. Additionally, implementing palliative programs to support a palliative approach are complex, and requires contextualization and tailoring to accommodate the specific needs of residents with dementia and health and social care providers working in the complexities of long-term care settings [68]. Therefore, understanding the views of health and social care providers could help in the development of organizational approaches, improve palliative program implementation, and target appropriate training and education.

CHAPTER 3: Study Objectives

The objective of this qualitative descriptive study was to explore the perspectives of health and social care providers working in long-term care on the use and optimal delivery of a palliative approach to care for people with dementia living in long-term care. The following research questions were examined:

1. How is a palliative approach to care being used with persons with dementia who live in long-term care?
    a) What are the perceptions of health and social care providers roles in supporting a palliative approach to care for persons with dementia?
2. What contributes to an optimal palliative approach to care for persons with dementia who live in long-term care?

CHAPTER 4: Methods

This chapter includes an overview of the qualitative descriptive design and a rationale for using this methodology for this study. Additionally, this chapter describes the study sample and location, participant inclusion and exclusion criteria, sampling and recruitment strategies employed, the methods and procedures for data collection and analysis, and the ethics procedures. The chapter closes with a statement on rigour and reflexivity.

4.1 Research Design

This study utilized a qualitative descriptive research design. Qualitative descriptive studies intend to discover the who, what, where, and why of events or experiences [97] and aim to provide a comprehensive description that is as accurate as possible and in the participant's language from the collected data [97,98,99]. Qualitative description is a method of naturalistic inquiry [99] that enables the evaluation of participants' experience with a minimal abstraction of data [100]. That is, the researcher stays closer to the data making low-inference interpretations during data analysis to result in the straightforward description of experiences and perceptions of the participants [97,98,101].

Two main elements of a qualitative descriptive research design are: (1) learning from the participants and their descriptions and (2) using the generated knowledge to influence policy and interventions [99]. Since the final product of a qualitative descriptive study is an accurate description of the participants' experiences presented in an easily understandable way to a lay population and professionals alike [99], this research design is a good fit for nursing and health science research [102] through its promising potential for use in improving health outcomes and services [99]. Further, this research design is well suited to research that aims to decrease health care barriers for vulnerable populations and groups of people who are typically overlooked [99]. Therefore, a qualitative descriptive research design was chosen for this study due to the applicability of the final product to provide useful knowledge for program and intervention implementation through the potential to provide clear information about the current state of a palliative approach to care in long-term care, and participant identified ways to improve care [99].

4.2 Inclusion and Exclusion Criteria

To be eligible to participate in this study, individuals had to: (1) be working in a long-term care home in Ontario; (2) identify as having experience working with people who have died with/from dementia; and (3) be able to speak and read English. The inclusion criteria were broad to ensure eligibility of various health and social care occupations with different job duties and levels of responsibility. Exclusion criteria included health and social care providers who do not work specifically in long-term care and providers who are not involved in the care provided to someone with dementia toward and at end-of-life.

4.3 Study Sample and Recruitment

This study took place in Southern Ontario, Canada. Participants who could offer in-depth, rich insight to answer the research questions were sought [103], thus, the study population included health and social care providers working in long-term care homes. The study aimed to recruit 1-3 participants per care provider group (e.g., physicians, nurse practitioners, registered nurses, registered practical nurses, personal support workers, occupational therapists, dietitians, dietary aides, spiritual support persons, and recreation therapists). To achieve this aim, purposive and snowball sampling were employed, both of which are appropriate for a qualitative descriptive study design [97,99].

Recruitment

Individuals across occupations of interest were recruited in the same way. Recruitment started in one long-term care home that was supportive of the study. Study information was distributed through signposting in high-traffic areas and on the long-term care home's communication platform. The communication platform is accessed by all staff within the long-term care home. In this initial location, a member of the management team further facilitated recruitment process by contacting individuals they thought would be interested in participating and sharing study information. Interested individuals were asked to contact the student investigator directly. In working with the member of management in this initial location, as data collection continued, they contacted individuals in specific occupations of interest. Snowball recruitment was also used and is detailed as follows.

Snowball Recruitment

In this initial location, snowball sampling took place whereby individuals who consented to participate were asked if they knew of other health and social care providers who might be interested in participating and were invited to share study materials with those people. Recruitment was expanded to various long-term care homes though this snowball sampling technique. That is, study information was also shared by individuals who consented to participate with key contacts in other long-term care homes and networks. Individuals who were interested in learning more about the study were asked to contact the student investigator.

4.4 Data Collection

Data collection took place from April to June 2021. Interviews were individual and semi-structured in nature and consisted of open-ended and questions and prompts. The interview guide (see Appendix C) was developed based on the literature and input from members of the thesis committee. Since the study sample consists of a diverse range of health and social care professions, a conscious effort was made during the guide creation to include only questions that could be answered feasibly by all participants. Several questions were made broad enough so that they would pertain to participants across different professions. As data collection progressed, questions and prompts were added or removed depending on the profession of the participant being interviewed as the relevancy of questions and new lines of questioning were determined [97]. Overall, the main topics of the interview questions included: the participants role and experiences providing care to residents with dementia toward and at end-of-life, the goals of providing care to residents with dementia, engaging the person with dementia in their future care, supporting family and caregivers, discussions regarding end-of-life and future care, timing and perception of palliative care/palliative approach to care, collaboration with colleagues, and their perspectives on an optimal model of a palliative approach to dementia care in long-term care, including areas where they feel they could benefit from support or more knowledge to provide that level of care. Questions were made more relevant to the individual participants experiences using prompts. Additionally, the end of each interview, participants were all given the option of adding anything they thought was relevant or that they deemed as important and was not discussed.

Descriptive field notes were taken during interviews to document contextual information pertaining to initial thoughts, and observations regarding participant's attitudes and behaviours related to interview questions and discussions which aided in the refinement of the interview guides throughout the data collection process. Reflective field notes were taken which reflect my personal account of what I was learning throughout the data collection process and included my impressions, ideas, feelings, possible categories for future data analysis and potential plans for future inquiry. Further, demographic information was collected to describe the characteristics of the study sample. Most of the demographic questions were asked at the end of the interview, with the exception of starting the interview's by asking the participants to identify their occupation in long-term care. Due to the present and ongoing COVID-19 pandemic, interviews were conducted either by phone or a virtual platform (e.g., Zoom, WebEx) depending on the preference of each participant.

4.5 Data Analysis

Qualitative description is a flexible design whereby data collection and analysis can be an iterative process by responding to participant's accounts and simultaneously adapting the analytical process as new insights are identified as the study progresses [104]. Research using a qualitative descriptive design often employ content analysis [105] therefore, following data collection, conventional content analysis was used to gain direct descriptions from study participants without imposing preconceived categories or theoretical perspectives [106]. Here, inductive category development [106,107] took place where codes were derived from the transcripts and used to inform categories that represented the descriptions from the study participants [106].

Following transcription, data analysis begun by reading all data repeatedly to achieve immersion and obtain a sense of the whole [107]. Then, in conjunction with the field notes taken during data collection, data was read line by line while making additional notes of first impressions, thoughts, and initial analysis. As this process continued, codes were identified that are reflective of the data [106]. Codes were then sorted into categories based on how they were related. That is, these identified categories were used to organize and group codes into meaningful groups that fits the data [106,108,109]. Investigator triangulation took place whereby the thesis supervisor reviewed the codes identified by the student investigator, providing input into the codes and categories that were identified [103]. The other members of the thesis committee reviewed and provided input into the categories and subcategories before they were finalized. The qualitative analysis software, NVivo 12 Pro (QSR International Pty Ltd., 2019), was used to support data management and analysis.

4.6 Ethics

Ethics clearance for this study was obtained from the University of Waterloo's Office of Research Ethics (ORE #42931). Further, this research study involved human participants, and therefore followed the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2.* One of the long-term care homes involved in recruiting participants also had their own review process that was undertaken to conduct research in that location.

To ensure participants had adequate information to decide if they wanted to participate and to ensure informed consent, participants were provided with a lay language Research Information Sheet about the study with a template of the verbal consent process. The Research Information Sheet included a brief overview of the research team, the purpose of the study, what can be expected as a participant, the potential risks and benefits, compensation, the type of data collected, confidentiality, voluntary consent, conservation of data, reporting of the study findings and contact information if they have any questions, comments, or concerns. Due to the COVID-19 pandemic, all research activities were conducted virtually, and verbal/implied consent was used. Attached at the end of the Research Information Sheet included a verbal/implied consent statement. This statement reiterated that this study had received ethics approval through a University of Waterloo

Research Ethics Committee and outlined the verbal consent script that was stated before each interview. As consent is an ongoing process, each participant was offered multiple opportunities, in writing through the Research Information Sheet and verbally at the beginning of the interview, to ask any questions and obtain additional information before, during, and after the interview. Additionally, prior to each interview, the participants were reminded that their participation was voluntary.

Once the data were collected and transcribed, participants were assigned an anonymous identification number and potentially identifying information (e.g., names, locations, places of work) were replaced with generic terms, such as "[long-term care home]". All study material and data, including the interview audio recordings, anonymized transcripts, and participant information and demographics were held on a secure, password-protected data storage system in the Faculty of Health at the University of Waterloo. The one document linking participants to their anonymous identification numbers was password protected and stored in the secure storage system. Only myself and my thesis supervisor had access to study materials and data. All materials and data will be destroyed according to University of Waterloo policy.

4.7 Rigour and Reflexivity

Being reflexive and practicing reflexivity is an essential component of the research process to demonstrate trustworthiness and ensure transparency [110,111,112]. Reflexivity occurs through critical self-reflection of how the researcher's own social background, assumptions, positioning, and behavior affect the research process [111,113]. I acknowledge that working in long-term care myself, and having had a grandparent pass away with dementia, have influenced my framing of this research study. Given my employment and personal experience, it was important that I practiced reflexivity at all stages of this study. As noted in section **4.5 Data Collection**, interviews and analytical data was supplemented with reflexive field notes that were taken during interviews [110]. Note taking not only aided in the refinement of the interview guides throughout the data collection process, but also provided essential context in the analysis process, and encouraged my reflection and the identification of personal bias [114]. To facilitate credibility, the data was analyzed for representativeness through reviewing the individual transcripts for similarities within and across the study participants [115]. Further, the process of peer debriefing took place with my supervisor and committee members [106,116].

CHAPTER 5: Results

A total of 20 interviews were conducted. The interviews averaged 46 minutes in length, ranging from 16 minutes to 2 hours and 10 minutes in length. Nine individuals were interviewed via Zoom and the remaining eleven were interviewed via telephone. Interviews were audio-recorded, transcribed verbatim, and anonymized for data analysis. Table 1 indicates the demographic information of participants. Participants held these occupations: activation manager, assistant director of care, dietary aide, nurse practitioner, occupational therapist, personal support worker, physician, recreational therapist, registered nurse, registered practical nurse, social worker, spiritual care provider. Due to the sample size (n=20) and number of occupations (n=12) in the sample, the exact number of participants in each profession will not be disclosed to protect the confidentiality of the participants. The sample included at least 9 long-term care locations. As not all participants identified which long-term care home(s) they currently worked in, the exact total of long-term care homes represented in the study sample cannot be identified. Of the disclosed long-term care home locations, they are all in Southern Ontario and a mix of privately and publicly owned.

Table 1: Participant Demographics

	Total
Age Range	
Under 30	3
30-39	4
40-49	3
50-59	6
Over 60	4
Gender	
Woman	17
Man	3
Other	0
Ethnicity, Race, Cultural Origin	
Chinese	1
Filipino	2

Hispanic	1
South Asian	1
White	15

Through conventional content analysis five broad and interconnected categories were identified: (1) Need for a Shared Understanding of a Palliative Approach to Care for Persons with Dementia; (2) Discussions About Goals of Care and the Future; (3) "End-of-Life Care" and Psychosocial, Grief, and Bereavement Support; (4) Need for Relationship-Based Care and Collaboration; and (5) Key Recommendations for an Optimal Palliative Approach to Care for Persons with Dementia.

Need for a Shared Understanding of a Palliative Approach to Care

The first category, *Need for a Shared Understanding of a Palliative Approach to Care for Persons with Dementia*, describes the variation in understanding of a palliative approach to care for persons with dementia demonstrated by participants. There were three connected foci that demonstrated this need for a shared understanding: the varied use of palliative approach terminology, how and when someone with dementia is recognized as 'palliative', and the provision of components of a palliative approach to care for people with dementia without the shared recognition the care being provided as components of a palliative approach.

Participants demonstrated varied use and understanding of "palliative", "palliative care", "palliative approach to care", "end-of-life", and "end-of-life care", amongst other terminology. Interpretations of when someone with dementia is 'palliative' ranged from an upstream recognition that everyone with dementia is 'palliative' by nature of having a terminal illness, to 'palliative' being equated to the last days or weeks of life.

A few participants recognized that everyone living in long-term care with dementia is 'palliative' by nature of having a life-limiting, progressive and terminal illness. This notion was further supported by the understanding that most people die in long-term care, and that this is their "last stop". Viewing dementia as terminal and warranting a palliative approach to care served as a prompt to view ‘palliative’ as encompassing more than end-of-life and dying. One participant stated:

> *“My perspective, 90% of residents that are entering long-term care that have a life limiting disease are considered palliative. Now that does not mean they’re end of life, that means they’re palliative because you can’t reverse that disease. This disease will take their life…So, majority of the residents that are entering long-term care are palliative and within a year to two-year timeframe they do become end-of-life and they pass.”* Registered Nurse

A few participants made the distinction between an upstream concept of “palliative” from terms with more prognostic implications such as “end-of-life care” or “actively dying”.

> “*There’s kind of the two approaches. So palliative, meaning we're really trying to give comfort care for their time here, and then there's an end of life, or actively dying.”* Assistant Director of Care

Other terms used by participants to signify someone is closer to death within being considered ‘palliative’ included the use of “acutely palliative”, “imminently palliative”, and “immediately palliative”. One participant indicated that a time frame within being considered “palliative” until death is needed for their work. Therefore, the term “imminently palliative” is used to determine how close to death residents are.

> *“…People on my caseload have been palliative for longer than like a year or two. So that's why people say, ‘Well, she's palliative’. And I'll be like, ‘well, palliative, immediately?... Is this going to be like less than six months? Less than three months.... someone who's more imminent?’”* Occupational Therapist

Most frequently, participants spoke to the application of ‘palliative care’ due to certain prompts, such as a “significant decline”, “major health event”, or “change in condition”. These prompts were described to trigger an assessment, at which point it is determined “whether or not to officially make someone palliative". In these instances, 'palliative care' was seen as care provided at a set time, which was at end-of-life and also used interchangeably with "end-of-life care".

> *"They slowly can't eat as well, their mobility declines. So, they can't walk anymore. They can't feed themselves anymore. It gets to a point where they can't do any of this for themselves anymore. Slowly they're not taking the medications, they don't want the medications, they don't want to eat anymore. You know that they may have more pain. So, then you start looking at palliative care, why have they got to that stage? Is there a medical reason or is it just end of life?"* Registered Practical Nurse

Many participants expressed that a resident with dementia is officially "diagnosed", "deemed", "officiated", and "labelled" 'palliative' when they are within days to weeks of dying. Even if the participants expressed a more upstream understanding of 'palliative', in practice, 'palliative' meant dying soon because "palliative care" is title of care provided at that point of significant decline or change in health. Two participants demonstrated their grappling with terminology in terms of timelines for use along an illness trajectory:

> *"We use a couple different indexes and ways to tell when someone's heading towards end of life. Palliative in the sense that they're not going to use life saving measures, really, I'd say most of our residents would be considered palliative in that way. Those considered at end of life, that's a little trickier to distinguish. And sometimes we think someone's really heading there, just this week we have a situation like that. But now this lady appears to be improving a little bit. And so, it's hard to tell how she is palliative, but there's ups and downs sometimes, too."* Social Worker

A couple of participants made general statements of when someone is 'palliative', discussed as the days to weeks prior to death. Most often in these instances being 'palliative' was associated with signs of dying and death approaching, such as "not eating and drinking", “difficulty swallowing”, “in bed and sleeping more”, “not talking or communicating”, and “aspirating”. Thus, these accounts represent the understanding of ‘palliative’ as ‘dying’.

Participants discussed providing many components of a palliative approach to care for persons with dementia. Most notably, participants across occupations emphasized keeping persons with dementia “comfortable”.

> *“It's always kind of focusing on comfort to making sure they're well cared for that they have available access to the activities and exercise and things that they can potentially manage, have time to spend with their families.”* Nurse Practitioner

> *“It's comfort, positioning. Protecting skin, maintain upright posture so that the person can eat and drink. Quality of life is huge for me, so they can engage with their family and be with their family, the family can take them outside safely to enjoy the outdoors.”* Occupational Therapist

One participant connected the terminal nature of dementia to the appropriateness of providing components of palliative approach to care. Namely, that “comfort care” can be offered from time of diagnosis throughout the illness and as needs change over time, comfort care takes a more prominent role.

> *“Just because someone's got dementia doesn't mean they'll pass from the dementia, generally, they will, but they might have a massive heart attack or stroke, that can happen to anybody. But it's saying that this is the natural progression of this illness. At what point do we elect to focus more on comfort care? That can be from day one, or that could be right towards the end. But at some point, comfort is going to be the goal because it can't be fixed. There is no cure for dementia…*” Physician

Pain and symptom management was also indicated as necessary to caring for someone with dementia throughout their time in long-term care. Attending to pain and the relief of other symptoms, along with addressing “restlessness”, “anxiety”, and “fear” to make them feel “safe” and “secure” was highlighted as core values in providing care.

> *“Pain management is huge. No matter whether death is imminent or death is a year and a half away, obviously, the pain should be treated, and we should try to help people to live their best.”* Social Worker

Often, the goals of providing care were described as holistic. Encompassing physical health needs as well as psychosocial health needs.

> *“Maintaining as much of their dignity as possible and their voice really, mostly comfort, trying to have them be pain free, you know, not agitated. And in a state where that all their emotional, social, that all of those needs are being met along with, you know, their physical needs.”* Social Worker

Participants also spoke to person-centered care and tailoring care to the specific needs of the individual with dementia.

> *“We're also looking at quality of life, the highest possible quality of life based on what's going on with them and how their dementia is manifesting”* Recreation Therapist

These results suggest that despite a lack of a shared upstream understanding of ‘palliative’ and a palliative approach to care, that is not to say principles of palliative care are not being used throughout peoples stays in long-term care. The care being provided is just not being recognized and articulated as ‘palliative’ in nature by most participants, until someone with dementia is “diagnosed” palliative.

Discussions about Goals of Care and the Future

The second category that was identified was *Discussions about Goals of Care and the Future.* Within this category, four subcategories were identified: (1) *Perceptions of timing and quality of care discussions,* (2) *Perceived challenges to engaging in care planning discussions,* (3) *Care discussions: whose role is it to be involved?* and (4) *End-of-life decision making.*

Perceptions of timing and quality of care discussions

The subcategory of *Perceptions of timing and quality of care discussions* encompassed the instances in which participants discussed the timing and quality of care discussions with persons with dementia and their families. There were variations across participant perspectives on the timing, consistency, and quality of identifying and reviewing the goals of care for someone with dementia and initiating future and end-of-life care discussions.

Participants discussed at what points reviewing “goals of care” for someone with dementia occurs. Time points ranged from “daily” (assessing and monitoring day-to-day care) to “annually” at care conferences, unless a significant decline or change in health prompted a discussion to review goals of care.

Many participants indicated that they “try to” or “usually” begin introducing concepts of palliative and end-of-life care and initiating these conversations upon “admission” to long-term care or at the first six-week care conference. For residents with dementia, there were inconsistencies in the level of detail available about wishes, values, and preferences in end-of-life care. Some participants reported that a clear picture was provided for what a person with dementia wants, which is put into a care plan for them to follow for their end-of-life, noting that things often change. While others felt that the care plans specific to end-of-life care are inconsistently and inadequately discussed or filled out except for cardiopulmonary resuscitation options and preferences.

> *“We do have end of life care plans in our system like point of care, but it's rarely filled out fully. It could be filled out way more.”* Activation Manager

Some long-term care locations worked with palliative care specialists who engage families in these end-of-life care discussions. Although, one participant indicated these discussions do not start right at the beginning of someone's care experience in long-term care and are framed as not including the individual with dementia themselves.

> *"We do also have a palliative care specialist, again, it's not right at the beginning of care. Typically, it's when there's changes and then it's like, okay, 'Where do you see this going? What are your hopes? What would your mother want? Or what would your wife want in terms of this? And have you talked to other family members? What are their thoughts about what's going on?"* Social Worker

End-of-life care conversations starting when a significant change in health occurs, signifying end-of-life is approaching, was a common experience. Most participants stated that revisiting a residents' wishes, preferences, and goals of care for current and future at a point of crisis or significant decline is not ideal. Although for many participants, that was the case. Participants expressed the need for these conversations to occur consistently earlier. A nurse practitioner indicated that in their experience, initiating conversations around future care and end-of-life preferences upon admission occurs too inconsistently.

> "*It varies. Ideally, there would be a good conversation when everybody came in. And ideally there would probably be a conversation as soon as you're even in that pre-long-term care admission when you're planning and those pieces. Sometimes that happens sometimes it doesn't... It's not as consistently early as I'd like it to be… Typically, here it has to do with, not as responsive, not eating and drinking. That's usually when we're starting to have those conversations a bit more."* Nurse Practitioner

For multiple participants, recognizing that dementia is a progressive terminal illness served as a prompt to initiate early discussions with family and care partners regarding future planning and end-of-life preferences. In this context, addressing eventual death because of the terminal nature of dementia right from the start was essential to providing high quality care and end-of-life.

Starting these conversations upon transition to long-term care may foster a sense of normalcy around the progressive decline associated with dementia. A physician shared:

> *"Explaining that dementia is a terminal illness, just a very slow and progressive terminal illness, but it is still the terminal illness. And since that's the case, what's the nicest way to make death take place? And that's planning for it from day one. Not waiting until something happens at the end, right."* Physician

Overall, even though some participants reported proactive discussions with residents and families about wishes and preferences for future and end-of-life care upon admission, the overall perspective of most participants was that of: "we don't them find out well enough" before end-of-life.

Perceived challenges to engaging in care planning discussions

The subcategory *Perceived challenges to engaging in care planning discussions* was emphasized by many participants. Some of the perceived challenges were discussed as specific to persons with dementia, while others extended more broadly. Although all study participants indicated that most persons living in long-term care have dementia, thus situating the broader perceived challenges to engaging in care planning as relevant to a palliative approach for persons with dementia. Challenges to engaging in care planning discussions included: perceived lack of capacity of persons with dementia, reluctance and discomfort discussing end-of-life, negative perceptions of death, perceived lack of time, and staffing models in long-term care.

Specific to caring for someone with dementia, participants articulated the dependent relationship between "capacity" and the ability to engage in their own care decisions. Presumptions regarding the perceived lack of capacity of people with dementia excluded their engagement in discussions regarding their current and future care. At the point of transition to long-term care, people living with dementia were seen as not having the "capacity" to meaningfully engage in discussions regarding their preferences and wishes for current and future care. Perceived lack of capacity of people with dementia did not prevent care providers from initiating and engaging in care planning conversations, however, these conversations aimed at specifying current and future care were automatically described as between care providers and residents' families or substitute decision makers.

> *"Sadly, usually in long-term care, they're past that point. So, the dementia is at a point where they're incapable of making those decisions. At that point, you're dealing with the power of attorney or substitute decision maker."* Physician

> *"For the most part, these health care decisions at the point where I see my people with dementia, so they're like pretty progressed at that point, the only input I'm seeing from them is either through an advanced directive that they have put in place for themselves, that expresses their wishes for end of life or through a substitute decision maker that they have assigned in the past to make those decisions for them in their best interest."* Recreation Therapist

Although there was a consensus that residents with dementia are not usually engaged in these care conversations themselves, all participants discussed the importance of honouring their wishes, values, beliefs, and preferences regarding their future and end-of-life care. Apart from the use of proxy decision-makers, this was accomplished through "looking at their wishes before they came into their home". Linked to the perceptions of people with dementia living in long-term care lacking capacity, if a resident's wishes and care preferences are undocumented or unspecified before transitioning to long-term care, there was a sense that engaging the individuals themselves in formal care planning conversations is out of care provider's hands and they have to trust that families and substitute decision makers can appropriately decide what the individual would want.

> *"That level of trust in the power of attorneys then if they haven't had specific conversations around those decisions, then they've certainly lived with those parent and children relationships long enough to hopefully honor making decisions."* Spiritual Care Provider

Some participants reported that many residents do not have their wishes and preferences for their end-of-life care documented. It was acknowledged that some people are reluctant to talk about death and dying and that discussing end-of-life care can be an upsetting experience. This reluctancy was said to prevent planning and preparing early enough in the dementia trajectory. When asked if many people with dementia have documented or made known their wishes, preferences, and values in some way, one participant said:

> *"I think particularly in the generation above me, it was something that a lot of people just sort of didn't talk about. Especially really to their loved ones, because you don't want to talk about difficult things necessarily. I don't find that very often at all unless somebody is like quite progressive in their thinking prior to all of this occurring."* Social Worker

While some participants indicated they are confident in initiating discussion about end-of-life and wants for future care, notably nurses and physicians, there are also participants who expressed considerable reticence and discomfort discussing death. Perceptions of death as something "not to be talked about" not only impedes persons with dementia and their families from engaging in proactive conversations but also limit care providers from initiating these conversations. An activation manager in explaining this phenomenon said that care provider discomfort and avoidance in discussing death and dying results in some people passing having not received their preferred end-of-life care.

> *"Then sometimes end of life, palliative care goes very fast. It's like today they're on end-of-life palliative and then in a day or two, they pass. You can't adjust it [plan of care] in two days. Plus, you can't really communicate with the resident. So, it could be done beforehand. Again, I think it's just that everyone's awkward with that conversation. They don't want to talk about that."* Activation Manager

Some participants stated that their specific education in palliative care was a facilitator of their abilities to approach sensitive conversations with families and residents at end-of-life.

> *"Because I am trained professionally in palliative care, I'm very comfortable having that conversation, to say, 'this is the time to pull back and there's hardly anything we can do to make them stay longer with us. It's time to look at comfort measures', and then I'm confident to talk to them about considering what they would want, not what you or I would want."* Registered Nurse

Participants spoke to feeling conflicted between being trained to "fix things" and "keep people living" and working in long-term care where death is commonplace, and they are required to support people in dying. The focus of many health care professionals' education on "saving" rather than supporting death and dying contributes to feeling uncomfortable and avoiding talking about death and dying.

> *"It's a topic [death and dying] that's really not talked about. I think everyone else...I don't know...avoids it. Obviously, we don't want people to die. Right. But it's very much an inner turmoil on a lot of health care providers too, right? Because we don't want people to die. It's just an ethical dilemma. It's tricky. That's all I can describe it as."* Registered Nurse

It was reported that culture play a role in perceptions on death and dying. A registered nurse stated that in their culture, death is a negative and avoided topic. Despite their initial discomfort, education was a facilitator in supporting a positive perception of death and more upstream understanding of a palliative approach to care and in turn, improved their comfort levels discussing death with families:

> *"At the beginning I wasn't a very comfortable to do that. It's my culture too, so I came from a different cultural background where death is not good thing. So, it's very hard to open that kind of conversation with family, but now I've become more educated. Educated with the palliative care approach and to understand the lifespan. It really made a big difference on me, that death can be good thing, it can be very peaceful and beautiful. So, that's how I started to feel like more comfortable to have a conversation with the families."* Registered Nurse

The capacity for consistent engagement in proactive and supportive conversations around wishes for future care, and end-of-life preferences were said to be hindered by workload and lack of time of physicians. Further, the time of admission may be perceived as too early for such discussions about death and dying.

> *"I think that's part of just time constraints for everybody, availability of physicians. And getting everyone settled into long term care then you feel bad kind of bombarding some families, you know, 'welcome to this new place, let's talk about end of life'. It does vary, certainly, we do try to connect when we can and get at least a sense of goals of cares."* Nurse Practitioner

Another participant, in recognizing that discussing death and dying on admission may be perceived as early, shared their approach to bringing up this topic with residents and families:

> *"Coming into the home and talking about that [wishes and preferences for end-of-life] and be like, 'Okay, I know, it's pretty far-fetched, but way down the line when you're palliative, what do you want to do?' I ask them that question."* Registered Nurse

Staffing models imposed by the long-term care system presented another challenge to proactive care conversations. A registered nurse discussed how in their experience, unregistered staff experience "anxiety" and "discomfort" having these discussions because of the emotions involved and not knowing how to initiate the conversation, and there are not enough registered staff to consistently engage families early.

> *"From my personal experience, I will do it [discuss end-of-life] very soon. But it's needed to be understood that in the system that's designed over here, there is one nurse for 30 residents, right? So, a lot of the nonregistered staff just are not comfortable having this conversation."* Registered Nurse

Care discussions: whose role is it to be involved?

The subcategory *Care discussions: whose role is it to be involved?* comprised of instances where participants discussed their perceptions of whose role it is on the care team to initiate and engage in care discussions with families regarding their loved one's end-of-life. Participants also discussed the need for improved collaborative involvement in formal care discussions such as in care conferences. In particular, many participants expressed concern that personal support workers and those in psychosocial and spiritual care roles are not provided the opportunity to be involved regularly.

Outside of formal discussions such as at care conferences, participants said that staff comfort levels, regardless of occupation, determined who discusses end-of-life with families. Although, those discussions were framed as informal and mainly just centering around the imminent death of the resident and "how they're doing". When discussing their involvement in conversations around values, beliefs, preferences, and expectations related to current and future care and end-of-life preferences, many participants automatically denoted that these conversations are medical focused, and therefore are the responsibility of nurses and physicians.

> *"It depends on the comfort level of the staff. I've even seen PSWs [personal support workers] if they were that comfortable, they say to the family "Do you know your mom is not doing too well", or even the cleaning staff they were very acknowledging of the resident and all their nuances and changes, but in reality, in actual determination of like, okay, let's have a discussion on end of life, it's the nurse on the floor"* Registered Nurse

> *"It's more the nurse that does that [speak to families]. But because we do a lot of hands on - some families want to know like how their day was or how it is going. But that's the only kind of conversations we have, other than that it's mostly the nurse."* Personal Support Worker

Similarly, nurses saw it as part of their responsibility.

> *"It's the lead nurse, I don't think it should be pushed off to anybody else, not unless the doctor or the nurse practitioner wants to speak to them [family]. I think it's our responsibility to be in that role. Because you know that person, you've worked with them, you've looked after them for X number of years. You are that lead."* Registered Practical Nurse

For some participants, since these conversations are medical focused, they are engrained as a responsibility of the nursing team. In this context, it is apparent a medical model prevails in some long-term care locations, emphasizing medical care rather than well-being and psychosocial care.

> *"I'm not going to lie, I go to some palliative care meetings, and I don't really say a whole lot, because they're speaking about medications and procedures. I don't know anything about that."* Activation Manager

Care conferences were discussed as the ideal setting to involve everyone from various roles to come together to support the resident and their families and discuss current and future care. All participants spoke to the interdisciplinary nature of care conferences. Upon further discussion, it became apparent that while some long-term care locations have "the whole interdisciplinary team" involved, most participants said that does not happen. In an experience where the "whole interdisciplinary team" is involved in care conferences, a participant explained what roles are included and what is discussed:

> *"The whole interdisciplinary team typically, so there would be the POA [power of attorney] or substitute decision makers, the physician or nurse practitioner, or both, one of the full-time nurses on the neighborhood that that person lives on. Physiotherapists, dietary representatives, so there's someone from most departments there to be able to speak to kind of their piece about how the resident is doing. So, during conferences, I am somewhat involved in them."* Recreation Therapist

Whereas in most participants' experiences, often many roles are not there or given the opportunity to be involved.

> *"I think the only people that attend the care conferences are the nurses, physician like... No, actually usually just the nurse, the dietary, the physio [physiotherapist] and the family member…The physician is never there."* Registered Nurse

Several occupations reported feelings of being undervalued and unrecognized. Notably, personal support workers, recreation therapists, activation managers, and spiritual support persons felt excluded from interdisciplinary team meetings, such as care conferences, which raised concerns about not being able to provide their perspective and critical knowledge of the individual from their discipline. Participants in those roles largely reported feeling "left out" of care conferences or "not in the loop" regarding hearing the wishes, preferences, and values of their residents, and in turn, they felt to have missed opportunities to support residents and their families. For participants in recreation roles, they felt particularly challenged in supporting "what's really going to reach their soul and spirit" at end-of-life. Such as favourite flowers and music, as well as wants such as "aromatherapy", "burning incense", and "eating ice chips".

> *"So having that conversation, having an okay conversation about that beforehand [before end-of-life], but just focus on recreation, along with everything else, but include recreation. Like, keep us in the loop of their wishes. I think there's much more that we can do that we're kind of like, not encouraged."* Activation Manager

Further, being involved in these care conferences was seen as an entryway to recognize where families may need additional emotional and spiritual support. A spiritual care provider shared several experiences where they realized families had "been living with guilt for months" and were not prepared for their loved ones passing. They felt that being involved in care discussions with families would support opportunities to provide more ongoing support throughout the care trajectory.

> *"Obviously, I need to be in correlation with the nurses so that we're not saying different things. But I see more and more the need for someone outside of that nursing team, who has a very certain perspective, who can take a bit of the time to really help families because especially with dementia, there are so many levels of grieving. One I was invited into, there was a fair bit of caregiving between family and I and that was around those end-of-life care and preparing for the end-of-life conversations. And I remember at the time thinking, 'I need to be part of these and yet that hasn't really come to pass and maybe I haven't asked enough…'"* Spiritual Care Provider

Spiritual care providers spoke to being "lumped in" with the recreation team despite the two occupations having distinct roles and responsibilities. Many participants reported that when families come in, they want to know how their loved one is feeling emotionally and if they are experiencing comfort "in a way their spirit, their heart, and soul are at peace". Thus, they found it "surprising" their roles are not supported to engage in these discussions.

Social workers positioned their occupation as "the natural fit" for engaging family members in early and ongoing discussions regarding values, preferences, wishes, and beliefs for future and end-of-life care. However, currently they are not engaged in this role.

> *"I think having those conversations about end-of-life care, or what people's wishes and values are, I think that's a really important role that we could play, that we're not doing so much at the moment. Social workers specifically are trained to engage in those conversations that aren't particularly easy… we're already inclined to ask those difficult questions that a lot of people don't want to go near."* Social Worker

Many participants who are not regularly engaged in formal care planning discussions, such as in care conferences, reported that they have their own approaches to getting to know their residents with dementia and inquire about their values, beliefs, preferences, and wishes for end-of-life care. However, it was often ambiguous how the obtained information influenced care provision or if there are protocols for documentation or information sharing for more seemingly informal discussions.

> *"Certainly, in my discussions with people, I will try to tease out that information, just in terms of: Who are they? What are their what's their belief system? What are their thoughts around death and dying?"* Social Worker

In discussing how their own roles are understood and included in care discussions, participants also talked to other roles they think need to be included. Unanimously, participants said personal support workers and spoke to how vital their role is. Both in providing care and in supporting others to provide care. Some participants viewed the lack of involvement of their own and others' roles (mainly personal support workers) as a result of a perceived lack of time, specifically when working with persons with dementia.

> *"The ones who actually provide direct care [personal support workers], they don't have the time. They have 30 people, and they don't have the time to hear these wishes in detail, right, if they could go, they would, but at the same time there's time constraints… It's a staffing issue at the end of the day."* Registered Nurse

End-of-life decision-making

The subcategory of *End-of-life decision-making* encompassed instances in which participants talked about preparing, engaging, and supporting families in making end-of-life care decisions for persons with dementia. Notably, participants spoke to the importance of shared and supportive decision-making to alleviate the burden on the family or substitute decision-maker. Experiences of conflict in making end-of-life care decisions and the ethical challenges of balancing family members' wishes and the individual's wishes and needs were also highlighted.

Participants frequently emphasized the importance of providing education regarding the dementia trajectory and dying process to families in their discussions, throughout someone's stay in long-term care. Observing and responding to residents' dynamic daily care needs acted as a bridge to anticipating future care needs and initiating conversations with families. Noticing a change in health encouraged care providers to initiate more frequent or in-depth conversations with families about preparing for making care decisions and end-of-life. Ensuring that families were aware that the individual is approaching end-of-life and are prepared to make care decisions was seen as essential. Both to support the well-being of those making difficult care decisions and so that the individual receives appropriate and preferred care. A registered practical nurse shared their approach to early and ongoing dialogue, identifying the importance of preparing families:

> *"It's an ongoing dialogue. You may communicate initially with them, maybe once a week, and then it just gets more and more… their thoughts, their feelings on end of life for their parents, what do they expect. So, it's just a gradual process, you've got to know where they're [families are] at."* Registered Practical Nurse

Decision-making at the end-of-life for someone with dementia can be ethically challenging for both families and care providers. Participants acknowledged the difficulties families face in weighing decisions around a loved one's life and death. Supportive decision making was a constant theme throughout discussing end-of-life care decisions. Participants felt that these decisions should be a collaborative and shared effort between families, residents, and care providers. However, as all participants indicated persons living with dementia lack "capacity" to be engaged themselves, it is unclear how shared decision making involves residents with dementia while in long-term care.

When family members and care providers disagreed on care decisions, participants spoke to the importance of providing education on the clinical course of dementia and the dying process as well as the impacts of each care option. For example, a registered practical nurse said: "We have to sit with family and explain everything. That the antibiotics are not working for the pneumonia. The steps involved to stop the antibiotics. He wasn't eating or drinking". Further, soliciting the opinions and recommendations from various care providers (e.g., physicians, nurse practitioners) was emphasized to support and reassure family members in making decisions to withdraw curative treatments. Similarly, in situations where family members were ambivalent in what care decision to make, it was important to participants that families felt supported by various professions in making these decisions.

> *"I don't want them to feel burdened with that decision at end of life on their own, I take part of that, collaboratively with them … I want them to be provided support by all of our inputs. So, when a family struggles with that, the end of life, I have a counselor as well talk to them, the nurse practitioner reiterated that it's the best interest of them… So then by talking… giving them reassurance of the whole team's perspective as well give her some emotional support, she felt better to make the decision."* Registered Nurse

Participants spoke to providing education on the role of the power of attorney to reorientate family's decisions to what they think the wishes would be of the person with dementia they are deciding for. This emphasizes the critical role care providers play in initiating potentially uncomfortable discussions and advocating for care decisions that both respect the values, preferences, and beliefs of people with dementia and support quality of life and death. A physician shared their approach to supporting families in considering what their loved one would want for themselves:

> *"I always say to families 'the job of the power of attorney is not to do what you want. We all want our parents, generally speaking to live forever, the job of the power of attorney is to recreate what your loved one would want'. I would always say 'if your loved one could go back 20 years in time when they were capable of making this decision, and they looked at their life now, would they want more aggressive treatment? Would they want hospitalization? Would they want treatment for pneumonia, or would they just want comfort?' And I think families have a lot less trouble when you pose it from their loved one's point of view."* Physician

Sometimes even when residents with dementia have documented their wishes, care providers must remind families and substitute decision makers that it is important to respect and honour residents wishes.

> "*His wishes were not to get a feed tube, and he also had aphasia. But that was his wishes, not to have that. And she [daughter] kind of had an ethical dilemma where she wished that he could live longer. But she couldn't oversee his wishes. And now that he had advanced dementia, he couldn't really make a change, but that was his wishes. So, she had to go and abide by that."* Registered Nurse

A registered nurse shared one of their approaches to reminding families to act in the best interest of their loved one:

> *"Sometimes even their [the resident's] presence at care conferences make families feel more reassured with a decision. By looking at the person and physically saying, 'I should probably keep their wishes in my mind' I feel like it's a trigger for them to know, okay, I'm doing this for them…"* Registered Nurse

However, participants also discussed situations where no amount of education, dialogue, or perspectives could influence families to make care decisions that care providers felt were in the best interest of the individual with dementia to have a "good" and "dignified" end-of-life. Participants felt that in these situations, it's out of their hands and talked about these deaths as "extremely sad". A physician shared an experience of when family members wanted "all the stops" and "everything possible" done to keep their loved one alive, despite this not being their recommendation.

> *"I've seen it and it literally breaks my heart for the resident and I can't control it. From day one … We have this discussion with the family that it's not realistic, and it means they're going to die in hospital. That it probably means that it'll be a more unpleasant death because it'll be CPR [cardiopulmonary resuscitation] initiated. And you go through, "what that's going to mean?" The family insisted and the person ended up in hospital and no longer in my care and had a feeding tube and a tracheostomy and was in the intensive care unit for a month. They ran a 45-minute code before she died. It all ends the same, the passing is just much worse. It was a 96-year-old with end stage dementia that died."* Physician

There is potential for conflict and disagreement between family members while making care decisions. There may be disagreements about who has the legal authority to make care decisions, whether to withdraw curative treatment, or planning after death arrangements. Social workers again positioned their role as well fitted to addressing family conflict.

> *"As a social worker, we always see these family dynamics come into play, and it's no different at end of life, it might even be amplified. But it's just so difficult, and so I think really highlighting our role, and being able to be part of the palliative approach is very important, because a lot of these things people aren't prepared to take on. Nurses might be very trained in palliative care, but they might not be comfortable dealing with all the family conflict aspect of it, or it can just be tricky, even like legally in decision making, figuring out who actually gets to decide these things. And are you acting in the best interest of your parent or for what this person would have wanted? So, it just gets very complicated."* Social Worker

"End-of-Life Care" and Psychosocial, Spiritual, Grief, and Bereavement Support

The third category that was identified was *"End-of-Life Care" and Psychosocial, Spiritual, Grief and Bereavement Support*. This category comprised of three subcategories: (1) *End-of-life for persons with dementia*; (2) *Supporting family in understanding their loved one's end-of-life*; and (3) *Loss, grief, and bereavement: support for family, residents, and staff.* Participants discussed how they identified when someone with dementia was close to dying. Overarching goals in providing care for persons with dementia at end-of-life were identified. That is, ensuring the individual was comfortable, providing appropriate care based on the individuals' wishes, ensuring no one died alone, and supporting the family. Across long-term care homes, participants spoke to the need to strengthen the resources made available to both families and staff in grief and bereavement.

End-of-life for persons with dementia

The subcategory *End-of-life for persons with dementia* encompassed where participants talked about how it's identified that someone with dementia is approaching their very end-of-life, and what the dying process looks like. Participants also spoke to the care they provide for persons with dementia at their end-of-life. While it was emphasized that each person with dementia is unique and thus their care is unique to them, overall, of importance to participants was that persons with dementia felt comfortable and had their psychosocial and spiritual needs met.

Across occupations, participants largely felt confident in their abilities in identifying when someone with dementia is close to dying. The "end-of-life period" for someone with dementia was said to look largely like everybody else's last period of life. All participants spoke about the discernible changes that occur in their last days and hours, such as "remaining in bed", "aspiration", "difficulty swallowing", and "not eating or drinking". Although it was noted that sometimes people with dementia decline extremely quickly. In situations where people did decline quickly, not recognizing when someone is "palliative" was discussed as "end-of-life" being suboptimal.

> *"But those situations are just like, it's hard… it's very hard for staff and residents, for them to go so quickly. And then you don't have that chance to provide the care."*
> Activation Manager

The importance of ensuring comfort at the end-of-life was emphasized by every participant and was considered no different for people with dementia. Comfort was discussed both in terms of physical care and emotional, social, and spiritual care. Participants identified supporting "comfort" through identifying and treating pain and symptoms, promoting skin integrity, providing mouth care, and ensuring people are at peace. Comforting someone with dementia during their last days and hours of life entailed physical touch, having what is "meaningful" to the person around them such as family, music, and smells, reminiscing and listening to their stories, and praying with them. Keeping people "happy", "calm", "peaceful", and "taking fear of death away" was consistently reported as essential in providing end-of-life care. Participants wanted people to feel "a sense of security" at the end of their life. An activation manager shared:

> *"Other than pain. All the rest is like spiritual to me. Yeah, happiness."* Activation Manager

Participants acknowledged that what might provide comfort to one individual with dementia may not be the same for another. While some interventions were provided automatically, like music, participants sought to elicit what is meaningful to the individual with dementia and their family. Person- and family-centered care was highlighted by all.

> *"I have one resident that I really connected with ...I knew her from when she was really in early onset dementia. She always made her bed…She was 95 she continued making her bed. Still to the end, she's like, 'I need to make my bed'. So, I went to make the bed with her like, I'm like 'okay, let's make your bed together'. I wheeled her in her wheelchair. And she felt that satisfaction, up to the end."* Registered Nurse

While the "end-of-life period" and the goal of providing comfort care at end-of-life were considered no different for people with or without dementia, participants did indicate that a nuance may lie in that people with dementia may not be aware they are dying or approaching their end-of-life. Participants frequently stated that they "don't understand that they're dying". Further, a spiritual care person acknowledged that "caring for someone with dementia has so many levels of loss of grieving along the way".

Companionship and "not being alone" at end-of-life was regarded as a key component of comfort for the individual. This was an area of passion for many participants, and it was frequently mentioned that staff would stay late and skip breaks to be with the individual who is dying.

> *"I honestly would skip breaks right through when people were palliative."* Registered Nurse

> *"Not infrequently, I'll see personal support workers after shift staying with residents, even if they have no families just so they're not alone."* Physician

Not wanting someone to be alone extended beyond providing company into ensuring someone with dementia *felt* not alone. Emphasis was put on those who provided care for them to be there and to ensure they felt “cherished”, “loved”, “safe”, and “secure”.

> *“I took several courses on end-of-life care. And the last thing they say that goes is the hearing. So, you just want to be able to show how much they were valued, how much we cared for them, because we've become their family…and a lot of times their family is not there.”* Personal support worker

Supporting family in understanding their loved one’s end-of-life

The second subcategory that was identified was *Supporting family in understanding their loved one’s end-of-life*. All participants held the ethos that they are meant to also support family members, not just the individual with dementia in their direct care. Supporting residents with dementia was seen synonymously with supporting their families. Many participants spoke to the importance of providing a compassionate and therapeutic presence to families leading up to and throughout the dying process.

> *“Yes, it's about the resident, but it's also about their family members coping with the last times they're with that person.”* Activation Manager

Part of supporting families was through providing them with education around end-of-life for someone with dementia. Many participants across various occupations reported that providing education around death and dying and the comfort measures available is a critical part of their role. Often, a collaborative approach was used to provide families with a comprehensive understanding of the dementia trajectory and dying process. Some areas that participants provided education on include aspiration, skin breakdown, behavioural and psychological symptoms of dementia, the progression of dementia, eating and drinking patterns at end-of-life, and medications and treatment options. A few participants emphasized that they take care not to answer questions that are out of their expertise in their role.

> *"…the end-of-life pieces has a lot of education around what's expected and it's a lot about the comfort measures, what we are going to do."* Registered Nurse

However, sometimes even with providing education around the pathologies of dementia and the dying process, some families still struggle accepting the extent to which their loved one's dementia has progressed and that they are in their end-of-life.

> *"…We have had a lot of conversations that are education, and still there is deniability, because they love their mom or dad and struggle to accept that the disease is taking over and that they are not eating anymore, or not making as much sense as they used to."* Assistant Director of Care

Some long-term care locations offered a "palliative package" or "palliative box" that contained educational pamphlets to families that explain the dying process for someone with dementia. However, educational supports offered to families varied dramatically across long-term care homes in the study sample.

> "*We don't have the education for the families to understand really what is going on with their loved ones."* Personal support worker

Loss, grief, and bereavement: support for family, residents, and staff

The third subcategory identified was *Loss, grief, and bereavement: support for family, residents, and staff.* This subcategory encompassed a great deal of variability. In particular, participant perspectives and experiences highlighted that the grief and bereavement support and resources provided to families differed in availability and quality across long-term care locations in the study sample. Participants also spoke to how they felt a personal responsibility to connect with and support families through reminiscing during their loved one's dying process. The need to support other residents, including those with dementia, and staff in grief and bereavement when someone with dementia dies was also emphasized.

There did not seem to be set standards or processes for care providers to provide grief or bereavement support to families, seemingly care providers would reach out on their own if they so wanted to. Many participants bluntly said there are no formal grief and bereavement supports or resources provided to families. Further, the culture in some long-term care homes was that of an expectation for the whole team to support familial grief more than others. One participant shared about their place of work:

> *"Well, activity aides do not enter any longer into that end palliative stage. Having said that, they do often still come in and talk with the family and say how much they were going to miss that resident… Our staff generally is encouraged to come in and to talk with the family."* Spiritual Care Provider

Many participants viewed visiting with families while their loved ones are dying as their personal responsibility. Participants across occupations spoke to reminiscing with families, stating they "share happy memories, talk about the resident and all of the fun things that they've done here". Reminiscing was seen as a way for families to grieve and process loss. The act of reminiscing seemed to emotionally support both the families and the care providers.

> "*I am going in and visiting with the family, sharing happy memories with them and providing emotional support while they are at the bedside. That's something I personally choose to do … I reminisce about the family members memories of that person, and just helping them kind of come to terms with it."* Recreation therapist

Those working in recreation careers felt they were well positioned to provide grief support to families, despite this not being officially part of their responsibilities. This is because members of the recreation team are often involved in learning about a resident's hobbies and interests, 1:1 and group activities with persons with dementia, and giving updates to families on their loved one's engagement and enjoyment in activities.

> *"In recreation, baseline you're often a lot closer with families, then maybe other members of the care team a lot of the time, you are in contact with them fairly regularly. And you have good relationships with these family members to begin with, even before you're in a situation where you have to kind of provide them with emotional support. I don't know that it's necessarily an official role, but it's something that I and many other recreation therapists that I know of kind of take on."* Recreation Therapist

A physician echoed this notion, acknowledging the role recreation therapists play in supporting personalized end-of-life care because of their close relationships with people with dementia and their families.

> *"If somebody loved opera, you make sure you got opera playing and etc., etc. Every situation should be unique for that person. And those are discussions that get held at care conferences, and often recreation is involved with those discussions as well. Because on a practical basis, they're the ones that are going to probably be finding whatever else is important to the person towards the end of their life."* Physician

It was expressed that having a relationship with the family or knowing the family for a longer time resulted in more staff reaching out at end-of-life and in bereavement. A participant shared their reflection on the feasibility of providing families with continued bereavement support after their loved one with dementia has died:

> "…*But because I still have that pastural heart, there is part of me that wishes I could do a bit more. And yet, there's no way, if I tried to do that outside of my role, where would it begin and end, right?"* Spiritual Care Provider

Many participants spoke about services and ceremonies that provide both staff and residents the opportunity to honour and pay respects to an individual who has died. Commonly mentioned were ceremonial walks, with titles such as "walk of honour", "dignity walk", or "code dove", where residents and staff line the hallways as the person is leaving the building. These ceremonial walks were expressed to be supportive in the grief and bereavement process for both residents and staff.

> *"We've had residents come to the code many times and they've been weeping. It's acknowledging they were a person who lived here, acknowledging this person was our friend."* Activation Manager

> *"We have in the home the dignity walk. They will make an announcement that also brings the team together to be stronger. It's also the bereavement process as well. So, we found those really make a difference."* Registered Nurse

Other services and ceremonies mentioned include celebrations of life and memorial services. Further, recreation therapists and activation managers said that they also create shadowboxes for the other residents on the unit where the individual passed and compile photos, videos, and artwork to send to families for them to "reminisce and remember their family member fondly". In some instances, participants in spiritual care roles indicated they are asked to be involved in funeral services.

A few participants also noted the importance supporting other residents in grief and bereavement, including those living with dementia. A spiritual care provider shared an experience they had in providing grief and bereavement support for a resident with dementia whose husband died. This participant acknowledged that in providing grief and bereavement support to someone with dementia, it is important to take care not to continually "reopen up grief" by reminding them that their spouse or loved one has died.

> *"I did a bit of grief support with her afterwards, I would watch for if sympathy cards came in the mail, and I would read them with her, or we talk about her husband and look at a picture and talk about how much he had loved her. And at this point, I don't know what she knows, it's hard to say... usually with someone with dementia we don't mention the loss of someone too much after it's happened. ... you could be told everyday your spouse died and go through the grief all over.*

> *We tend to if someone asks for a spouse, we'll often have an agreed upon you know, 'oh he's resting'."* Spiritual Care Provider

Participants discussed emotional attachments to people with dementia they care for and their families, describing themselves as extended family to the residents, and likewise, stating that residents are their "family" or "second family". Because of their relationships, residents' deaths are extremely emotional for care providers. Many participants highlighted their need for grief and bereavement support from their employers. Participants reported feelings of being supported by other staff, but there was insufficient emotional support from management.

> "*Not at my workplace. Definitely not by management we are not supported that way at all. We are from each other. Because we can all discuss that individual's fun times, or what a blessing it is that that person has moved on…But in general, we do not have the support that I feel we should have. Especially because we are caring for these people, we don't get three days off to grieve."* Personal support worker

Huddles and "debriefings" were held by participants as a way to support each other after someone has died. This was not a standard process across all participant experiences, and it was said to depend on the team they work with. One participant indicated that these debriefings not only aid in grief and bereavement support for care providers but also helps them to grow as a team to strengthen their end-of-life care for persons with dementia.

Need for Relationship-Based Care and Collaboration

Permeated throughout the data is the fourth category of the *Need for Collaboration and Relationship-Based Care*. Within this category, two subcategories were identified: (1) *Building relationships with persons with dementia and their families* and (2) *The need for collaboration in providing a palliative approach for persons with dementia.* Building relationships with residents with dementia and their families was seen to be essential to providing a person- and family-centered palliative approach to care. At times, participants discussing collaboration and roles are points of tension in the data; participants all agreed that collaboration is essential for providing care for persons with dementia, stating "we have to help each other" however, inclusive and effective collaboration did not always occur.

Building relationships with persons with dementia and their families

The first subcategory identified was *Building relationships with persons with dementia and their families.* Building genuine relationships and bonds with persons with dementia and their families was seen as important across all study participants. For many, being cared for by someone you trust and have a relationship with was emphasized as instrumental to supporting quality of life and death for persons with dementia. Thus, many participants highlighted the importance of continuity of care, particularly at end-of-life, within a palliative approach to dementia care.

Participants spoke to how providing a palliative approach to care for people living with dementia required knowing the whole person and not focusing solely on medical care. Building intimate relationships with people with dementia was discussed as mutually beneficial. That is, beneficial for both the individual and the care provider as "knowing the resident" helps care providers identify care needs and ensures the individual receives more person-centered and individualized care.

> *"It's about person-centered care, and really being as specific as possible, getting to know the person with dementia, hearing about who they were before dementia, from their family. I think all of those things are extremely important and being able to provide that care."* Social Worker

This goes beyond a philosophy or best practice of person-centered care, into forming genuine bonds with residents. Participants discussed building authentic "relationships" and the importance of trying to relate to people with dementia. A personal support worker shared that:

> *"The important thing is how you relate to the residents, how you talk to them. These residents [with dementia] know if you care for them or not… They can feel it, and they can see how much you really care for them."* Personal Support Worker

Participants associated a palliative approach to care with promoting "quality of life" through providing emotional and spiritual support throughout someone's stay in long-term care, not just during their last days and weeks of life. Many participants spoke to "taking extra time" to try and get to know people living with dementia to promote their "well-being" and meaningful social engagement.

> *"I take extra time to figure out what are some of your favorite hymns?... Many people have five or six songs and their commendations that they have grown up with, and they have sung over and over again, and they can join in to them even in their progression of their illness [dementia]."* Spiritual Care Provider

Having relationships with residents with dementia was often talked synonymously with building relationships with families. Many participants noted that a key factor contributing to the development of *meaningful* relationships with people with dementia and their families depends on the amount of time they've known them.

> *"Knowing them a little bit longer. For me, it has been helpful when I work with our dementia residents to establish a connection with the family as well, too."* Spiritual Care Provider

Providing care to people with dementia that was consistently delivered in a familiar environment by consistent staff with who residents' have relationships was seen as fundamental to relational and person-centered care. Explaining that continuity of staff can create a "peaceful" environment where people living with dementia feel "safe". Hospitalization was seen to hinder and undermine continuity of care. Although there were situations where hospitalization was appropriate, several participants spoke to the importance of managing what they can in the long-term care home. Particularly at end-of-life, participants viewed hospitals as unideal environments for people with dementia. Not because hospitals do not provide good care, but because the staff at the long-term care home have relationships with the residents, and the long-term care home is just that, residents' home.

> *"The best-case scenario is aging and dying in place. When the person is becoming end of life, there should be some ability for the person to remain in their room and receive the care that they need there."* Social Worker

A physician advocated for caring for residents' end-of-life in their "homes" and "own beds" surrounded by care providers they have built relationships with. This was expressed as a moral obligation of their role as a physician.

> *"I tell families that if your loved one passed in the hospital, I consider I haven't done my job, I've kind of failed you. I explain to families from day one that, when someone's time comes, it's much nicer to pass in your own bed and pass with the personal support workers and nurses that have known you since day one, on your admission. It's nice, it's just a better passing."* Physician

The need for collaboration in providing a palliative approach for persons with dementia

The second subcategory, *The need for collaboration in providing a palliative approach for persons with dementia* encompassed where participants discussed the higher need for teamwork and interdisciplinary collaboration to provide a palliative approach for persons with dementia. Participants highlighted collaborating with members of the care team within where they worked, as well as with external consultants. While interdisciplinary collaboration was seen as essential across all study participants, the quality of collaboration varied greatly amongst participant experiences. In particular, a lack of role clarity and a hierarchy of roles were said to impede effective interdisciplinary collaboration.

The goals of care within a palliative approach for someone living with dementia were thought to be no different than for someone without dementia, namely, "maximizing quality of life". Although, the approach taken to provide care for those with dementia was described as a different approach to other residents, without dementia. This approach was centered largely around teamwork and collaboration, with team members using a "therapeutic approach" consisting of using their "soft skills".

> *"You have more than one person helping you with it. Someone to hold that person's hand so that the nurse can get her vitals done. If they're feeling scared, there's a slightly different approach [to dementia care]. For sure. It's just all breaking down the fears, because they're not really understanding sometimes, right?"* Recreation Therapist

Beyond collaborating and working as a team to perform daily care, the most frequently discussed forums of interdisciplinary collaboration included care conferences (as previously discussed), palliative care committees, and working with palliative care consultants and specialists.

These committees were expressed as a way to work as a team and collaborate around palliative care. Much like care conferences, the intent is that a member from each discipline should be part of the committee so that there is an interdisciplinary lens and approach to providing and improving palliative care. However, much like how care conferences were branded as an opportunity for interdisciplinary collaboration but often roles were excluded, palliative care committees were also said to be missing a representative from each department. Some participants said that their long-term care home is meant to have a palliative care committee, although they are "currently non-existent", and this was seen as a significant problem.

Working with external consultants and other resources were described as beneficial in providing a palliative approach to dementia care. Participants worked with palliative care specialists, local geriatricians, and various palliative care programs through hospice. One participant noted working with a geriatric psychiatrist. Several participants spoke to working with outside consultants, such as pain and palliative nurses, on "challenging" and "complicated" cases where care providers are "struggling to manage symptoms and pain is not addressed" for persons with dementia. Some of the consultants that participants work with were said to also share resources and provide ongoing learning opportunities in palliative and end-of-life care topics.

Often disconnects while working as an interdisciplinary team to provide palliative and end-of-life care were due to role clarity and differing perceptions of the scope of roles. Participants spoke of tensions when they worked in non-medical professions, and they noticed signs of pain or discomfort in residents. Many shared when they tried to bring this to nursing staffs' attention, there was the sense that they were "stepping on toes". A recreation therapist shared their perspective on the tension between medical and non-medical occupations in providing a palliative care at end-of-life:

> "*I'm trying to take care of their souls while the nursing team is trying to take care of their bodies sort of thing. And sometimes there is a disconnect between those two perspectives because it's, it's hard for one side to, to see the others perspective, when we're both focusing on very different aspects of the palliative care experience."* Recreational Therapist

How other occupations understood others' roles could work to enhance or hinder a palliative approach to care. On the enhancing side, when participants had strong relationships and understandings of their team's expertise, an interdisciplinary approach comes to fruition.

> *"When so many people are working in one place, there are so many different kinds of things that we do for the residents. We all aim for… we are there for the residents, but it is how you do it… I think it's very important to involve everyone."* Personal Support Worker

However, some participants felt their ability to contribute to a palliative approach to care is denied by how other professions understood and valued their occupation and were aware of what expertise they could offer. An activation manager shared:

> *"There's a lot of stuff recreation can help with that we're not consulted on. Even room changes of residents and what would work for that family and what will work for that resident. I think we have a lot of input that we could be offering*."

Some participants described a hierarchy of roles that challenges working together as a team and collaborating to provide a palliative approach to care. Notably, participants holding non-clinical or unregulated professions (i.e., personal support workers, recreation therapists) reported that their knowledge of the residents and their role specific expertise were often undervalued in decisions about residents' care. A social worker expressed how they understand why some people "get defensive" and feel "disempowered" if they feel they are not able to provide the care they want to because their opinion is not valued.

> *"We actually had a personal support worker, on the [palliative care team] along with our registered practical nurses and the registered nurses. They were saying it's hard sometimes because the doc or the team lead, who's a registered practical nurse, doesn't necessarily listen to the personal support worker's perspective. And its sort of that hierarchy, they're [personal support worker] not listened to, the registered practical nurses feel they're not listened to, and have very little power, because the doctors prescribing the meds."* Social Worker

Sometimes, this hierarchy of roles impeded the recognition that someone with dementia is approaching their end-of-life.

> *"She [a personal support worker] says, 'I've had to be pushy, depending on who the nurse is', sometimes it's been her that's getting the nurses to see those changes, but they were kind of like, 'yeah, but it can be this, could be that', and not calling the family soon enough to get family in there….personal support workers are doing the hands on care, the feeding, they're the ones in there with the resident when they're going to get them up in the morning, not the registered nurse, right?"* Spiritual Care Provider

As demonstrated in other sections of the results, participants not occupying a personal support worker position often talked very highly of personal support workers. Specifically concerning this context, how essential they are in providing critical information to nursing staff based on their intimate knowledge of residents with dementia that may signify transitioning into end-of-life.

Lack of information sharing across occupations sometimes limits the end-of-life and dying care provided for people with dementia. This results in those individuals not receiving their set out wishes and preferences. Participants in recreation roles said that if they were off work and someone passed away, their team members would not know what to provide for their dying residents with dementia. In discussing how personal support workers are not involved in care conferences and therefore miss the opportunity to hear individual's preferences, values, and wishes for their end-of-life, a recreation therapist said:

> *"[Everyone] should be either involved in the care conference or debriefed after the care conference, to hammer in those concepts about that resident's personal and palliative care wishes ... those things aren't delivered to the rest of the team, particularly the personal support workers who are providing direct support for these residents and are spending lots of time caring for them. If I had to ask someone of my personal support workers, 'Hey, if this person was made palliative on the weekend that I'm off, do you know what kind of music but on for them? Do you know what they would want?'"* Recreation Therapist

Recommendations for an Optimal Palliative Approach to Care for Persons with Dementia

The final category represented participants' recommendations for an optimal palliative approach to care for persons with dementia in long-term care. Participants identified seven key recommendations, including: clarifying roles, improving grief and bereavement supports for staff, improved staffing and funding models appropriate for the care needs of persons with dementia, timely and consistent care planning discussions, improving end-of-life resources, improving the built environment to better suit the needs of persons with dementia, and providing staff with continuous and accessible education regarding palliative approaches for persons with dementia.

Recommendation 1: Clarify roles in supporting a palliative approach for persons with dementia

Participants recommend that in a palliative approach to dementia care, staff members need to be supported to work to their full scope of practice within a collaborative effort in supporting palliative and end-of-life care. Many participants that did not occupy professions such as doctors or nurses felt that their palliative care responsibilities need to be acknowledged and normalized as part of their job duties. If providers were supported to contribute to a palliative approach to dementia care, it could mitigate residents who are "palliative" being "sidelined" from receiving "social, emotional, and spiritual" support since the expectation of those roles is to be programming for residents who aren't labelled palliative and "who are living".

> *"Much of recreations quality measures are "How many programs did you run today?", "Did you run exactly the things that you did on the calendar?" We need to normalize the fact that palliative care is going to sometimes take away a little bit of time from some roles doing what they would usually be doing. And making sure that those norms are established, and that that's okay. Because there are palliative needs that are overshadowing some of the other tasks that we might be doing in a day. We've got to normalize the fact that time does need to be spent on palliative care and effort does need to be put into it. I'd like to see that in an optimal model"*
> Recreation Therapist

Participants also discussed the need for culture change in their long-term care home. Culture change was discussed in terms of hierarchy of roles and attitudes of staff. In terms of attitudes of staff, participants expressed needing an organizational shift to a "can do" attitude in supporting end-of-life preferences and wishes. For an activation manager, this is also linked to the importance of supporting those in recreation roles to contribute to end-of-life care.

> "*We need more openness, a 'can do' attitude. Like, what can we do? To be able to say if the resident or the family wants it… Yeah, we got you, we got this. If it's seeing that one son or daughter who lives out in BC [British Columbia], if it's seeing my dog, if it's seeing the sunrise, reaching Friday. I don't know, some people have it in their mind, this is what I need to do before I can let go. And if we can reach that for the person to be peaceful, I'm all about it…"* Activation Manager

Suggestions to improve working collaboratively with staff members working to their full scope within the care team included: opening lines of communication with doctors, having outside consultation to help with staff dynamics, and strengthening leadership.

Recommendation 2: Support staff with loss, grief, and bereavement

Long-term care organizations must recognize that caring for dying persons is emotionally difficult work. As employers, there is a responsibility to provide supports and services that protect their employee's well-being.

> "*We need more debriefing more support… I think that would benefit everyone. If you have a staff that's supported and feels empowered to be providing palliative care, I think everyone benefits from that. I don't know if that's just more education, or changing the culture a little bit, too."* Social Worker

Further, care providers working conditions consist of heavy workloads and chronic understaffing. The need for better staffing ratios extended beyond being able to provide better care to those living with dementia, but also to be able to support the care providers in their own mental health and well-being when dealing with loss and grief. For example, when discussing areas where they felt they could be more supported, a personal support worker indicated understaffing and increasing workloads having a compounding effect:

> "*We need to be better equipped to walk away at the end of our day, because we're still living. That person has now moved on to another role in their life, wherever*

> *that may be for them. But we have now just witnessed another death. And that I believe, takes its toll on people whether they want to admit it or not. And it needs to be clearly addressed in long term care, so that they have healthy employees. Sure, they talk about 'Make sure that you take time out for yourself, that you did this, that you did that', well, there's a shortage of personal support workers. We're working more hours; we're doing more stuff... we're just doing things with less resources."* Personal support worker

Recommendation 3: Improve staffing and funding models to be appropriate for the care needs of persons with dementia

More staff is needed to provide higher quality family- and person-centered care for persons with dementia within a palliative approach to care. Understaffing is a longstanding challenge that is characteristic of the long-term care sector. Many participants became emotional when talking about how the care their residents with dementia deserve - the care they want to provide - is not possible under the current long-term care staffing ratios. While the link to a palliative approach to care for persons with dementia was not always made explicit by participants within this recommendation, the described reasons for improved staffing and funding models to improve quality of care, life, and dying for persons with dementia would serve to support the provision of a palliative approach.

Participants consistently emphasized that caring for persons with dementia requires a person-centered and family-centered approach in which there is increased teamwork and staffing needs. Although as described my participants, the reality is that there was not enough staff or time to optimally meet the daily care needs of their residents with dementia. Again, much of the care they discussed are components of a palliative approach to care, just not articulated as such. Many said in an ideal model for a palliative approach to dementia care, that the staffing ratio would be one care provider for every person living with dementia. However, many expressed a lack of faith that staffing ratios would be improved to the levels they felt are necessary to provide better physical, psychosocial, and spiritual care for persons with dementia. Therefore, participants indicated they felt one staff to four residents with dementia is a more realistic ideal.

> *"Because each resident is so individualized. Their needs are so different. They all have a different lifestyle. And at the end of the stage of dementia, they all need reflecting on the past, so the caregiver ratio needs to be one to four, no more than that. So that they have time to understand the resident, they have time to support them, and they have time make them feel better."* Registered Nurse

Further, the current model of funding was expressed as not appropriate to support dementia care. For example, one participant compared how the current "medical model" of funding does not consider "each individual resident" living with dementia and "individual behaviours", further stating:

> "*I really feel like dementia residents need a lot of funding. The current funding is more based on medical model. If you have a skin wound, you might qualify more funding. Let's say if you have IV [intravenous] therapy, you get more funding. I work with dementia residents, dementia residents demand way more time than just giving IV [intravenous] to residents. I think the government itself has to look at that as a whole as this population needs more support."* Registered Nurse

Recommendation 4: Timely and consistent care planning discussions

Several participants' optimal model of a palliative approach to dementia care involves consistent and "proactive conversations" (ideally on admission) with residents and their families regarding goals of care, what they want in terms of future and end-of-life care, and general information about the resident with dementia and their family that could be used to promote quality of life. Some attributed the current lack of proactive engagement was a result of a lack of time and human resources.

> *"Engaging the families earlier and in really defining what their goals of care are. Because I think we do it, but I don't think we do it well. I think it's rushed and*

> *quick…'Do you prefer to just sleep in till 11 o'clock?', and we can make that okay, and really have that individualized care be important."* Assistant Director of Care

An activation manager suggested having a standardized form that all residents fill out, so care providers have this information available when the time comes.

> "*Even just filling out a little form of 'what would you like, in the room, whether a certain scents like smells or certain music or certain visuals, or who will likely be with you? And what did they need?'"* Activation Manager

Additionally, suggestions included pre-admission support. Multiple participants stated that there should be support in the pre-admission stage for preparing and supporting people with dementia and their families to have these discussions regarding their beliefs, values, preferences, and expectations and specifying care goals and end-of-life preferences.

> *"I think that coming into the home with family having that discussion prior when they're early onset, or even if a person gets diagnosed with dementia, before they were admitted when they're relatively understanding of what they want. Then coming into the home and talking about that on admission, like 'Okay, I know, it's pretty far-fetched, but when you're palliative, what do you want to do?'" Registered Nurse*

Another suggestion for improving goals of care and care planning discussions with families included the addition of a role dedicated to these discussions:

> *"Ensuring there is someone within your staff team that is that link and getting those conversations to happen in pretty significant ways and time is given. Not just sort of someone who is your family liaison, but really their job is all about something else... and so they really can't give justice to that."* Spiritual Care Provider

As previously reported, social workers felt well-positioned to take on this role. However, many long-term care homes do not have social workers. Participants recommend ensuring that there is someone responsible for having conversations about future and end-of-life care. In a similar vein, a registered nurse indicated how computer documentation left little time for relational care and expressed that hiring a role to support nurses dedicated to care planning would allow for an adequate time allotment to both bedside nursing and improved care planning.

> *"It felt like I couldn't do the care that I wanted because I had to meet a deadline... We do care planning which we could probably hire another nurse to do all of that."* Registered Nurse

Another previously discussed problematic area regarding a lack of proactive goals of care and care planning discussions was the avoidance and discomfort of talking about death and dying. Many of the participants in talking about an optimal palliative approach to dementia care emphasized how imperative it is for shifts in perceptions of death and dying to occur. One participant indicated that the concept of a palliative approach to care needs to come up at diagnoses:

> *"I think ultimately, the palliative approach, it needs to come up when you have any of these chronic diagnoses. And it's not that it's your end of life is now, but it's like this disease will get worse…I think we're making gains, there's still some people who are never going to want to talk about death and dying…but I think it's just normalizing that conversation more and more."* Nurse Practitioner

While other participants spoke to wider societal shifts in perceptions of death and dying:

> *"In terms of how we support the death as more so than just the death or the week of the death…death needs to be part of our conversations, in and out of normal living, because death is part of life."* Spiritual Care Provider

Recommendation 5: Improve the availability and quality of end-of-life resources

Having resources for end-of-life available and ready to go for someone with dementia and their families was of great importance across study participants. Many participants spoke to the quality and quantity of resources, such as “palliative care carts”, “comfort carts”, and “snack carts”, they want to provide at the very end-of-life. Participants said that having these resources readily available is essential as some persons with dementia can move from “stable to palliative care pretty quickly”. When resources were not available, this was said to possibly result in persons with dementia and their families experiencing suboptimal end-of-life and resident’s not receiving their wishes for end-of-life (e.g., favourite music, spiritual care).

> *“You want something that's professional, you walk in you go ‘here, a beautiful cart for you to celebrate your end of life’... We need organization, we need to buy all new stuff. ... I'd like it to have lots of nice sensory smells, music. Lots of things to drink ...a nice fan to move the air, magazines to read, a Bible. Kleenex boxes. We need to make sure that we have adequate supplies and make sure all these carts are always replenished and ... available at a moment's notice.”* Recreation Therapist

Recommendation 6: Improve the built environment to better suit the needs of persons with dementia

Another recommendation for an optimal palliative approach to dementia care included the need to change the environment. This was discussed in two ways, the first being the addition of “palliative care rooms” and the second being to reconceptualize the entire current structure of long-term care homes and rebuild to better suit improving quality of life and social interactions for persons with dementia.

Palliative care rooms were recommended and described to provide “privacy”, “dignity”, and “respect” to the resident and their family during the dying process. Participants spoke to how a private room would afford the ability for residents and families to personalize the space and create a home-like environment, which would improve end-of-life experiences. Participants connected palliative care rooms to the type of setting provided in a hospice:

> *"You're dying in that same room with them. Come on! Afford them the dignity to die with grace and honor. In another room, surrounded by as many loved ones as would want to be there. It just doesn't seem fair… Why should they not have that? We would do that for somebody in hospice… why can we not do that here?"* Personal Support Worker

Some participants discussed what could be included in these rooms, such as:

> *"Where there's comfortable chairs to sit in, there's a beautiful bed for them to lay in. There's their favorite music, their favorite blanket."* Personal Support Worker

In terms of reconceptualizing and rebuilding long-term care facilities, participants spoke to the need for more personalized spaces that support the autonomy and independence of persons with dementia. While participants did not make an explicit link to a palliative approach to care, redesigning the built environment of long-term care homes to better suit persons living with dementia was seen as fundamental to improving emotional and social well-being, improving overall quality of life, and the management of physical and psychological symptoms, which are in line with the aims of a palliative approach. Environments should be designed in a way that is more "welcoming", "homelike", and "bright and peaceful" while also supporting people living with dementia to safely "do whatever they want". Safe access to the outdoors was seen as essential for all people living with dementia in long-term care, regardless of the stage they are at in their trajectory.

> "*Less institutional for sure. I think a lot of the residents that are exit seeking, it'd be really cool to have a very home-like, or neighborhood-like environment that they can be not confined to an area. Where they can go and pick up a coffee… make them feel like they're not contained. Really keep their independence as much as possible*." Assistant Director of Care

Recommendation 7: Provide continuous and accessible care provider education

When participants were asked what an optimal model of a palliative approach to dementia care would include, almost unanimously, participants said education: “educating all the staff would be important”, “it’s all about ongoing education”, “I'd love to see more education”, and “the big thing is the education”. The need for education in a palliative approach to care was highlighted because many participants said this was insufficient in their training.

> *“I think it depends on your like school. I'll be honest, my program didn't really talk about palliative care.”* Registered Nurse

> *“It wasn't required of my recreation therapy training.”* Recreation Therapist

Orientation and support for new long-term care staff related to a palliative approach to care is needed.

> *“There's no training whatsoever. You come out of school, and they're like, “Here you go, here's long term care and you're gonna learn on the job” kind of thing. There's no structured learning whatsoever. So going into long term care, palliative care was something so new.”* Registered Nurse

A commonly held perspective was that a palliative approach to care should be a foundation in many care providers educational programs and mandatory in long-term care homes for continued learning

> *“You need to be educated, and to take that education to heart, when it comes to palliative care. I'm telling you it should be absolutely mandatory that there be courses offered and almost forced on people who are in long term care, it's the end goal here.”* Personal Support Worker

Continuing education in a palliative approach to care should be covered by the long-term care home or the Ministry of Health and Long-Term Care. Participants across professions indicated that if they wanted to take a course on palliative care or dementia care, they would likely have to pay for it themselves and do it on their own time, which acts as a deterrent. Two participants stated:

> *"There's not often a lot of money for those kinds of things. I think just being able to have educational opportunities, like in services that are brought here."* Spiritual Care Provider

Long-term care organizations should provide role specific refreshers and updates on best practices. Many participants said that this is "necessary".

> *"They should have a small educational program for personal support workers, just to kind of give them a refresher every so often."* Personal support worker

Nursing staff indicated a dire need for current and incoming nurses to be more appropriately trained on pain control, as it was reported that many nurses' skills and knowledge on pain management is inadequate. Particularly the proper use of "pro re nata [pro re nata – medication taken as needed]" prescription of pain medication. This training must address potential fears of this medication use hastening end-of-life.

> "We *need to teach the younger nurses. I think that's what we need to do about palliative care about pain control, pain management, you know, when you have an order for pain management, and it's a PRN, people don't get it. That's one of my big things. People don't realize that when you give them these medications, you have to give it on a regular basis to keep them comfortable."* Registered Practical Nurse

The participants expressed the need for education in many topics regarding a palliative approach to care. Namely, the application of a palliative approach specifically for people with dementia, expressing sympathies and condolences, palliative versus end-of-life care, and discussing future and end-of-life care. A personal support worker also specified needing education that would equip them to provide respectful care of the body after death.

Another learning need regarding the application of a palliative approach to care for people with dementia related to understanding different religions and belief systems. One registered practical nurse stated:

> "*The big thing is the education on different religions, different beliefs, you still have your personal support workers who are hesitant to go in and do care on these residents… you don't always know everybody's beliefs*." Registered Practical Nurse

CHAPTER 6: Discussion and Conclusion

This study utilized a qualitative descriptive design to explore the perspectives of 20 health and social care providers regarding: (1) how a palliative approach is being used with persons with dementia in long-term care, (2) their perceptions of providers' roles in supporting a palliative approach to care for persons with dementia, and (3) what contributes to an optimal palliative approach to care for people with dementia in long-term care. These questions were of interest because in Canada, most persons living in long-term care have a form of cognitive impairment or a diagnosis of dementia [63,66]. Previous work has established that persons with dementia receive suboptimal palliative care in long term care settings [1,14,26], and due to Canada's aging population and increasing prevalence of dementia, an increasing number of persons with dementia will require an appropriate palliative approach to care in this setting [61,66,70]. Thus, there is a clear imperative to investigate current practices and improve palliative approaches to care for persons who live with dementia and for those who develop dementia in the future. Furthermore, while there has been increasing attention paid to palliative approaches for persons with dementia and in long-term care settings in Canada in recent years, examining a palliative approach specific to those living with dementia in long-term care remains relatively absent from the literature beyond identifying barriers to the provision of care. Therefore, of interest to this study was exploring the current use and recommendations for a palliative approach to dementia care in long-term care. The study aims were accomplished by providing an in-depth look into the experiences and recommendations of a wide range of health and social care providers who work with persons with dementia in long-term care. Thus, this thesis builds upon the existing Canadian literature, and in turn can help to inform the development and improvement efforts of palliative care programs for persons with dementia in long-term care.

There were three salient and overarching threads woven throughout the study results that address the examined research questions, including: (1) Moving in the right direction toward a palliative approach to dementia care, (2) Health and social care providers need support, and (3) Recommendations for an optimal palliative approach to dementia care in long-term care.

Moving in the Right Direction Toward a Palliative Approach to Dementia Care

A palliative approach to care is a family- and person-centered, upstream approach that focuses on meeting a person's and family's physical, psychosocial, and spiritual needs, at all stages of a chronic progressive illness [1]. A palliative approach to dementia care includes communication regarding illness prognosis and trajectory, advance care planning, psychosocial and spiritual support, pain and symptom management, regular opportunities to review goals of care, and grief and bereavement support [1,13,56].

All participants in the current study noted that most persons living in long-term care have some form of dementia, therefore, any improvements to palliative approaches in long-term care must consider the needs of persons with dementia due to the nature of the long-term care population. The results from this study, like previous research [49,52,117], reinforce that there is not a shared understanding of what exactly a palliative approach to care entails for someone with dementia. While study participants discussed many components consistent with the principles of a palliative approach as described by The Way Forward [1] and the European Association for Palliative Care white paper on defining optimal palliative care for persons with dementia [8], there was variation in how these components were defined and discussed. While aspects of a palliative approach are being used for persons with dementia, based on the results of this thesis, it appears as though the approach is not fully integrated, and is not practiced consistently according to study participants, across the long-term care locations included.

Participants used 'palliative approach' terminology to refer to either a philosophy of care, or a service provided at end-of-life, or both. While some participants described 'palliative' as an upstream philosophy to care for persons with a terminal illness such as dementia, most participants automatically equated a 'palliative approach to care' to 'palliative care' which was described most often as the care provided at the end-of-life stage. Participants spoke to the application of palliative principles prior to the end-of-life stage; however, most participants did not conceptualize or articulate that the care they were providing aligned with the principles of palliative care (or a 'palliative approach to care'). Thus, as they cared for people with dementia throughout their stay in long-term care, palliative principles were applied before residents were officially "deemed palliative" or were considered to be receiving "palliative care". For example, across occupations, participants emphasized the goal of comfort and enhanced quality of life for persons with dementia. "Comfort" was discussed in terms of physical care as well as psychosocial and spiritual well-being. Further, all participants emphasized the importance of family- and person-centered care and the ability to spend quality time with their loved ones within a palliative approach for persons with dementia. The care that participants described are core tenants of a palliative approach, even if they are not aware that this is what they are describing. Indeed, research has pointed towards a lack of conceptual clarity as a barrier to providing quality palliative care [49]. A palliative approach involves adapting and integrating palliative care principles and values into the daily care received by persons with dementia, thus, findings from this study indicate that there is a clear need to clarify terminology and conceptualizations surrounding palliative and end-of-life care and how they fit into the wider philosophy of a palliative approach.

Contrary to previous studies [26,118,119], many of the current study's participants recognized that dementia is terminal, and that the progressive nature of the disease warrants the provision of palliative principles when delivering care. For some participants, recognizing dementia is terminal and that persons in long-term care will likely die there led to an upstream understanding that those with dementia benefit from the principles of palliative care (e.g., comfort care, spiritual care) prior to the formal designation of being "palliative". This recognition could bridge an upstream understanding of a palliative approach for those with dementia. McCleary et al. (2018) [50] suggest that training and education can help long-term care staff to see the link between end-of-life practices and person-centered approaches already being used.

A palliative approach and dementia

Results from this study demonstrate that the outcomes of comfort and quality of life within a palliative approach are not necessarily different for persons with dementia, rather that the approach to care and the human and financial resources required to provide an optimal palliative approach to care differ for persons with dementia. For example, in providing a palliative approach for persons with dementia there was a higher need for a collaborative team-based approach to provide quality care, a shared and supportive approach to end-of-life decision making, building relationships with the resident and their family, and continuity of care.

Unlike previous studies [50], participants across occupations in this study did not report difficulties in recognizing when someone with dementia is dying and close to their end of life, just that decline and death may occur quickly, and therefore there is a need to be proactive rather than reactive in planning and preparing for end-of-life. Consistent with existing literature [89], , the current study's results demonstrate variability in health and social care providers' confidence in initiating discussions about planning for end-of-life care and death and dying. Negative perceptions of death and dying are a barrier to early end-of-life planning discussions for persons with dementia, their families, and care providers. Similarly, Sutherland et al. (2019) [49] found that personal support workers' and nurses' discomfort talking about death was a barrier to end-of-life discussions with families of persons with dementia in long-term care. Advance care planning is a vital component of a palliative approach for persons with dementia [1], and the need for advance care planning to be consistently occurring in long-term care is increasingly recognized in the literature [120,121]. Advance care planning is a process that supports adults to understand and share their personal values, wishes, beliefs, and preferences regarding future physical, psychosocial, and spiritual care to help ensure people receive care that is consistent with their values, wishes, beliefs, and preferences in situations where they are not able to express their wishes [122,123]. In long-term care, these conversations should occur early with persons with dementia and their families. While the current study's participants spoke extensively about preparing families and providing education regarding the trajectory of dementia and what end-of-life looks like in dementia, participants did not explicitly state or discuss "advance care planning". However, the results demonstrate that the importance of following residents' wishes, beliefs, and values are a priority for health and social care providers in the current study.

Like other studies [124], discussions regarding end-of-life were described as inconsistent and inadequate, and as more challenging with those who have dementia. The perceived loss of capacity led to persons with dementia being excluded from the opportunity to be involved in such discussions. While it is widely acknowledged that many persons living with dementia will require a proxy decision maker in the advanced stages [122], as stated by Heckman et al., [125] capacity is both time and decision specific. A person's capacity changes and needs to be reassessed every time a decision is required [125]. It was not clear from the study findings how care providers determined a resident's capacity to be engaged in these discussions. Care providers should try to engage and support residents with dementia as much as possible to participate in discussions around their care [122]. Some research has demonstrated that persons living with dementia in long-term care are willing, wanting, and able to engage in discussions regarding their current and future wants, preferences and wishes for care [126]. Goodman et al. [126] highlight that when supported and given the opportunity, persons with dementia living in long-term care can articulate their preferences and priorities for care and end-of-life. Practice and processes need to be developed to ensure persons living with dementia are engaged in care decisions and planning for their end-of-life. Results of this study thereby may suggest that an integrated approach to advance care planning is necessary along with training on how care providers can engage persons with dementia in these discussions. There are several resources that can support care providers in engaging in advance care planning with persons with dementia and their families. For example, Advance Care Planning Canada created Essential Conversations [127], which is a guide to advance care planning in long-term care. This resource offers guidance specific to discussions with persons with dementia. Further, Canadian researchers are currently developing and evaluating a standardized person-centered advance care planning intervention in long-term care homes which is informed by the needs of persons with dementia [125].

Due to the progressive cognitive decline associated with dementia, there is a high degree of family involvement within a palliative approach due to their role in proxy decision-making. Participants highlighted their personal ethos of ensuring families felt supported in decision-making, as the "burden" should be shared and not be on one person. Shared decision-making is a collaborative approach to making care decisions that involves the individual, their family, and their care providers [128]. The shared decision-making approach emphasizes being person-centric, aiming to involve the individual themselves [128]. In the case of the current study, participants spoke to collaborating with members of the care team to support families in their decisions, although as previously noted, the persons with dementia themselves were not engaged directly. Cranley et al., (2019) [123] conducted a study in a Canadian long-term care home aiming to develop strategies to support shared decision-making among residents, their families, and staff.

The authors identified five strategies that they consider essential to facilitate shared decision-making in long-term care, including: train staff to communicate effectively with residents and family, strengthen personal-support worker and family relationships, involve personal-support workers, facilitate open and proactive communication with residents, family, and staff, and involve the management team [123].

Perceptions of roles in supporting an interdisciplinary palliative approach for persons with dementia

Results from this study highlight that interdisciplinary collaboration in supporting a palliative approach for persons with dementia needs to improve. This was particularly salient when participants spoke about attending care conferences and engaging in care discussions as members of the care team. Priority in care conference scheduling was said to be given to those in medical professions (i.e., members of the nursing team and physicians). Personal support workers and those occupying psychosocial and spiritual care roles had minimal participation, and in some experiences, persons in these roles were excluded from care conferences fully. These results support work done by Durepos et al., (2018) [129], who studied family care conferences in four long-term care locations in Ontario and found similar patterns of nonparticipation.

Notably, the results from this study suggest that to improve interdisciplinary collaboration within a palliative approach, members of the care team need a better understanding of their colleagues' roles and capabilities. While some participants in the current study attributed the limited involvement of personal support workers to lack of time, others felt that a hierarchy of roles, resulting in a lack of understanding and appreciation of personal support workers' role in supporting a palliative approach for persons with dementia excluded them from these opportunities. Similarly, the current study's results demonstrate that those who provide psychosocial and spiritual care also experienced barriers to working to their full scope of practice within the interdisciplinary care team due to a lack of understanding of their role from persons in nursing roles. These were interesting and novel findings as every other participant holding a different occupation talked highly of personal support workers and those in recreation roles, emphasizing the intimate knowledge they have of their residents with dementia and the essential care they provide. These were key results of this study as a lack of interdisciplinary collaboration and a perceived lack of role clarity were discussed as contributing to instances when palliative and end-of-life for persons with dementia and their families was suboptimal. Further, health and social care providers feeling challenged to provide care for persons with dementia due to a lack of role clarity from their colleagues may result in decreased job satisfaction.

Previous research has also found hierarchy of roles as an impediment to interdisciplinary collaboration and providing high quality palliative and end-of-life care for persons with dementia [50,130]. Clarifying occupational roles in supporting palliative and end-of-life care for persons with dementia among care teams may work to mitigate power struggles seen in the hierarchy of roles described and support persons to work to their full scope within care teams. Brault et al. (2014) [131] state that clarifying occupational roles and defining responsibilities can ensure appropriate implementation of each occupational group's role and optimize occupational groups scopes of practice. Sutherland et al. (2019) [49] state that more research is needed to examine how long-term care staff work within power dynamics of interdisciplinary teams regarding facilitating end-of-life care decision-making discussions. The current study's findings support this recommendation for further research.

Health and Social Care Providers Need Support

This study's results demonstrates that while health and social care providers have an understanding that dementia is terminal and require palliative principles, further improvements are needed to support moving this understanding into practice in the long-term care setting. Notably, this research highlights that to achieve an integration of a palliative approach for persons with dementia, health and social care providers need to be supported at the system- and organizational-level and by their colleagues. Participants in the study felt challenged at the organizational- and system-level in their ability to provide high-quality palliative and end-of-life care to those with dementia and their families. Like previous research [49,95], participants most notably discussed understaffing, heavy workloads that are task-focused instead of person-focused, and a lack of time to provide person-centered care suited to the needs of persons with dementia. For example, while the psychosocial and spiritual needs were well understood as important for persons with dementia, funding models and system challenges (i.e., understaffing) hindered persons with dementia from receiving adequate levels of meaningful engagement. Other studies have reported that residents with advanced dementia are often left alone in their rooms and spend most of their days doing nothing, with very little meaningful engagement [132,133]. Enhanced quality of life is a core component in a palliative approach for persons with dementia, understaffing and lack of time to provide meaningful, person-centered care need to be addressed systematically to support long-term care's success in integrating a palliative approach.

Grief and bereavement support are integral components of providing a palliative approach to care, however evidence suggests that support is often lacking for families, staff, and other residents [77,134,135]. The current study's results demonstrate that health and social care providers think that grief, bereavement, and emotional support for themselves and their colleagues should be a part of a palliative approach to dementia care. Participants spoke about their family-like bonds with their residents with dementia and how emotionally challenging it is when someone dies. Participants expressed relying on support from their colleagues to process their grief and bereavement through informal "debriefing" and "huddle" sessions to reminisce after a resident died. However, many noted that there was no time to properly debrief with peers following a death, since care providers are required to return to work promptly to continue focusing on residents still under their care. These findings are like previous research investigating palliative approaches for persons with dementia in long-term care [50,77]. Supporting staff in their loss and grief when persons with dementia decline and die is an important part of end-of-life care [89]. There is a clear need for supervisors and management to acknowledge the family-like relationships and bonds staff across occupations form with persons with dementia and provide adequate support for the loss and grief staff experience when their residents die.

Recommendations for an Optimal Palliative Approach to Dementia Care in Long-Term Care

Another key contribution this study makes to the literature is recommendations for an optimal palliative approach for persons with dementia in long-term care. The recommendations discussed below have the potential to inform the development and quality improvement efforts of palliative programs and models of palliative care. Participants made seven recommendations that span the dementia trajectory, from planning for future and end-of-life care at an earlier stage of dementia to grief and bereavement care after death.

Role clarification in supporting a palliative approach for persons with dementia

The first recommendation was the need for role clarity in contributing to a palliative approach to care for persons with dementia. It should be made explicit how each role in a long-term care home supports palliative approaches for persons with dementia. Particularly, providers in roles that support psychosocial and spiritual well-being of residents with dementia need to be supported in their full capacity to provide care for persons with dementia who are dying. These providers felt that their role in supporting persons with dementia who were dying was limited due to their role centering around programming for residents who are not palliative. Other Canadian studies have found that role clarification amongst nurses and health care aides is required for an integrated palliative approach [91]. The current study extends those findings by demonstrating that occupations beyond nursing and physical care also require role clarity to support their contribution to an interdisciplinary palliative approach for persons with dementia.

Supporting staff with grief and bereavement

The second participant-identified recommendation for an optimal palliative approach to dementia care was the need for improved grief and bereavement support. While participants noted a gap in adequate grief and bereavement supports for families, the primary focus of this recommendation was on the need for grief and bereavement support for staff. Participants stated that they need formal debriefing following a death and need recognition from management of staff grief and loss. Marcella and Kelley (2015) [134] sought to understand nurses' and personal support workers' support needs and experiences of grief and bereavement working in long-term care in Thunder Bay, Canada. Like the present study's findings, participants in the Marcella and Kelley (2015) [134] study said they were confronted with grief daily, yet that there was no organizational support to address their grief. Marcella and Kelley (2015) [134] made eight specific recommendations for managers in long-term care to guide policy and procedure development, for example, implementing a palliative care education program for staff that includes strategies for managing grief and loss, making grief and bereavement resources accessible to staff for their own grief and to offer bereaved families, implementing organizational level procedures to support staff such as peer-led debriefings after every death, and providing time and resources for staff to reach out to residents and their colleagues after someone dies [134].

Improved staffing and funding models

The third recommendation was the need for improved staffing and funding models to better support the care needs of persons with dementia. Participants in the current study recommend a ratio of one care provider to four persons with dementia. The current study's findings suggest that caring for persons with dementia under a palliative approach requires a high level of teamwork amongst interdisciplinary care teams and thus reaffirm and stress the need for governments to commit to hiring more health and social care providers. Of importance is that there is also a commitment to invest in educating and training care providers to ensure they have the competencies to care for persons with dementia within a palliative approach. There is a substantial body of literature reporting that increased staffing is linked to a higher quality of care and improved care experiences for residents [136,137]. This literature also demonstrates the link between higher staffing ratios and improved job satisfaction, reduced staff turnover, and lower levels of staff burnout [136,137].

Within this recommendation is also the need to improve funding models for long-term care settings in Ontario to better suit the care needs of persons with dementia. The health and social care providers in the current study recommend a shift away from the current "medical model" of funding that does not appropriately recognize the individualized care needs of persons with dementia, nor the time required to provide that care. In 2019, the public inquiry into the *Safety and Security of Residents in the Long-Term Care Homes System* [138] released its final report with 91 recommendations for the improvement of long-term care in Ontario. Of these recommendations is the need to improve funding models to better suit the increasingly complex care needs of persons making up the long-term care population. Like the current study's results, the report indicated that there are gaps in funding coverage for persons with dementia [138]. It was stated that the highest level of funding that can be provided to support personal expressions associated with dementia is inadequate to cover the more costly and time-consuming care required to meet the needs of residents with dementia [138]. The recommendation from the report concludes with a call to action from the government to review and improve funding models in long-term care to address this gap [138].

Timely and consistent future and end-of-life care planning discussions

The fourth recommendation was the need for proactive and consistent future and end-of-life care planning discussions with residents with dementia and their families. Participants in the current study emphasized that future and end-of-life care conversations consistently occur too late and need to be broached earlier with families. Ideally these conversations would start at the time of admission to long-term care or while persons are on the waitlist for long-term care homes, and there should be support for advance care conversations from point of diagnosis. In evaluating a Canadian palliative approach program in long-term care, Kaasalainen et al. (2019) [139] similarly found that early discussions regarding wishes, values, and beliefs for future care are lacking in long-term care and not are integrated into the trajectory of care. Stakeholders in the study questioned the feasibility of implementing advance care planning in long-term care. Like this recommendation, Kaasalainen et al. posit that advance care planning may be better suited to occur prior to transition to long-term care [139].

In terms of supporting proactive and consistent care planning discussions *in* long-term care, the current study's participants recommended the addition of a role occupied by social workers dedicated to advance care planning and facilitating end-of-life conversations with residents and families. Munn et al. (2008) [140] sought to explore end-of-life experiences in long-term care from the perspective of residents, family members, and staff. Participants in that study recommended an increased involvement of social workers in long-term care as this might contribute to improved collaboration among stakeholders, thus enhancing end-of-life experiences for persons dying [140]. As social workers are not currently a mandated occupation in long-term care in Ontario, this role will require training to mitigate potential ethical dilemmas and conflict among or between staff, family, and the resident with dementia in end-of-life decision making.

End-of-life resources

The fifth recommendation was the need for end-of-life resources. To improve the end-of-life experience for persons with dementia and their families, participants highlighted the importance of having resources available and ready to go. Resources included palliative care carts or comfort carts that contained music, aromatherapy, reading materials, sacred texts, grief and bereavement information, tissue boxes, a fan, snacks and beverages, and pens and paper. Hill et al. (2018) found that administrators who were more committed to the goals of palliative care allocated funds for resources more willingly [55].

The built environment

The sixth recommendation was to improve the built environment to support the living and dying of persons with dementia. In the current study, participants spoke to how long-term care homes are not designed to support quality of life and dying or the autonomy of persons with dementia. Participants recommend the addition of palliative care rooms to ensure dignity and privacy during someone's end-of-life. Brazil et al. (2004) [141] conducted focus groups with various care providers in six long-term care homes in Ontario, Canada to explore their perceptions of what constitutes quality end-of-life care. Like the current study, Brazil et al. [141] identified several themes related to the importance of a supportive environment such as privacy at end-of-life for the person dying, their family, and the dying persons' roommate. Further, in the current study, redesigning the built environment of long-term care homes to better suit the needs of persons living with dementia was seen as fundamental to improving emotional and social well-being, overall quality of life, and the management of physical and psychological symptoms, which are congruent with a palliative approach. Notably, homelike environments that maintained the autonomy of persons with dementia and allowed for safe access to the outdoors were recommended. Several studies have reported that the built environment of long-term care homes affects quality of life [142] and the provision of palliative and end-of-life care for persons with dementia [143]. Findings from the current study support those of Giesbrecht et al (2021) [144] who found the importance of considering 'place' and design in the construction of long-term care homes to ensure they are conducive for palliative care (e.g., private rooms, smaller scale). A very recent Canadian study conducted by Harasym et al. (2020) [84] has called for policymakers and administrators to consider re-designing the physical and social environments within long-term care to better support the palliative and end-of-life needs of residents.

Continuous and accessible care provider education

The seventh and final recommendation for an optimal palliative approach to dementia care model was for continuous and accessible education. Palliative education should include: the application of palliative approaches for persons with dementia specifically, occupation specific learning (e.g., pro re nata medication use for nursing staff), religious and belief systems, palliative versus end-of-life care for persons with dementia, discussing end-of-life, and expressing sympathies and condolences. Efforts need to be made to provide continuing education and training for care providers already working in long-term care. Foundational palliative education should be mandatory for all long-term care staff. The cost of educational opportunities was identified as a barrier to participation. Thus, providing continuing education in a palliative approach to care for persons with dementia should be the responsibility of long-term care homes or the Ministry of Long-Term Care. Of particular importance to the current study's participants, long-term care homes should ensure their nursing staffs' capacity to optimally manage pain for persons with dementia. As many of the current study's participants indicated positive experiences in working with external palliative care specialists and consultants, a possible recommendation is using those connections to upskill nursing staff's capacity in managing pain for persons with dementia.

The recommendation for providing health and social care providers in long-term care with education on a palliative approach to dementia care extended into recommendations for the improvement of education provided to the future workforce. Improvements need to be made in undergraduate and graduate training for health and social care providers to have core palliative care knowledge and occupation specific skills related to the needs of persons with dementia.

While the need for ongoing education to support an integrated palliative approach is not a new finding [77,91,95,145], this study demonstrates much improvement is needed to ensure health and social care providers feel equipped to provide a palliative approach to those living with dementia in long-term care. There are multiple palliative education programs suited for use in long-term care by a range of care providers that have dementia care as a learning outcome. For example, the Pallium Canada's LEAP-LTC course [146] and the Fundamentals of Hospice Palliative Care [147].

Situating the Current Study and Further Directions

Canadian researchers have found that adopting a palliative approach to care must take place across the entire home [148], notably requiring management and leadership support [149]. This study, like others, demonstrates that a change in culture is needed to fully integrate a palliative approach to dementia care across the home [1,72]. Encouragingly, work is currently being done in Canada regarding culture change and a palliative approach in long-term care. Importantly, work in long-term care culture change is being used to inform palliative approach programs and models. For example, the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) is a multiprovince program that is evidence based and endorsed by long-term care staff and stakeholders [72]. Persons living with dementia in long-term care have participated in the SPA-LTC program and the Palliative Care Toolkit provides resources specific to dementia. Another program, called Namaste Care is intended for persons with moderate to advanced dementia and engages them in multisensory therapeutic and meaningful activities to enhance quality of life and dying [150,151]. A recent feasibility study by Kaasalainen et al., (2020) [150] found that after residents attended the Namaste Care program, their quality of life and pain improved, and medication costs decreased. The authors concluded that the study's findings support the implementation of the Namaste Care program in Canadian long-term care homes, although larger scale testing is needed.

While the current study's findings and recommendations can help to inform palliative frameworks, programs, and models through providing a dementia-specific focus, it is important to reiterate that health and social care providers need support in their provision of a higher quality palliative approach for persons with dementia. Participants in the current study felt deeply challenged to provide a higher level of palliative or end-of-life care for persons with dementia than what they already are. The challenges and needs discussed by the participants are not anomalies to specific long-term care locations or even across countries. In the context of Canada, these challenges and barriers have been expressed many times and signify the dire need for a system-wide shift. The current long-term care system does not provide the human or financial resources health and social care providers need to provide family- and person-centered palliative approaches to care to those living with dementia [68]. The results of the current study and existing literature in this field demonstrate the systemic nature of barriers and issues in the long-term care setting and clearly indicate the need for policy and human and financial resources toward supporting quality of care provision and receipt in long-term care.

Due to the progressive nature of dementia, a person's ability to make informed decisions declines over time [3,7]. As noted by Heckman et al. (2020) [125], in Ontario, consent to treatment is required at the specific time a treatment decision is required, although people can express their wishes and goals for future care to guide their substitute or proxy decision makers. Therefore, as demonstrated in the current study's results and in previous work [89,125], advance care planning is a vital component in a palliative approach for persons with dementia. However, the current study's results demonstrate that persons living with dementia in long-term care are not currently engaged in advance care planning due to the dominant perception of their lack of capacity. Further research is needed on how to engage and support persons living with dementia in advance care planning, both before transition to and while living in long-term care. A human rights-based approach may serve useful in examining this phenomenon [152]. Additionally, further research about the needs and lived experiences of persons with dementia in long-term care within a palliative approach is required.

Since many findings in the current study support and extend existing literature on this topic, the importance of bridging the gap between research and practice is clear. While researchers should continue to share findings that are both novel and support or extend existing literature on this topic, efforts need to be put in determining how to support the adoption and implementation of identified recommendations for an optimal palliative approach to dementia care. These findings reinforce the need to account for contextual differences between long-term care home environments and members that make up care teams when considering program and model development and application. Future research should explore the context and characteristics of long-term care homes that have been successful in the integration of palliative care programs and palliative approaches to dementia care. Further, the current study's findings and recommendations, and similar existing evidence, should be used to guide evaluation and quality improvement efforts of existing palliative programs and models appropriate for persons with dementia being developed in Canada [58,72,125].

Strengths and Limitations

Methodological strengths of this study include the diversity and breadth in the sample with respect to the occupations of participants and number of long-term care homes represented by the participants. Long-term care homes included a mix of privately and publicly owned homes across various regions in Southern Ontario. The sample size of the current study (n=20) is comparable to other studies using a qualitative descriptive approach [153]. Interviewing 20 health and social care providers allowed for deep consideration of the current use and optimal model of a palliative approach to dementia care. However, as this sample was made up of several different occupations (n=12), the sample in each occupational group did not permit for a deeper analysis into the perception of roles within occupational groups. Further, in synthesizing the results between 12 occupational groups, contrasting opinions and nuances may not have been described in depth. Future research may consider either a larger overall sample size or recruiting participants from a single occupation to facilitate a deeper understanding of the perceptions of specific roles in supporting a palliative approach for persons with dementia.

While the goal of qualitative research is not to be generalizable and the current study's sample size was appropriate and allowed for depth in perspectives, this study does not include all health and social care providers or staff that contribute to a palliative approach to care for persons with dementia in long-term care. Further, the perspectives of persons living with dementia in long-term care and their families were not included in the current study.

The current and ongoing COVID-19 pandemic was a limitation as conditions brought forth by the pandemic likely influenced study recruitment. The pandemic has immensely impacted the long-term care sector, particularly in Ontario. Health and social care providers are being stretched to unbelievable lengths and are working in increasingly challenging and dangerous settings. Participating in a research study was likely not a priority for many.

The sample population may be biased towards individuals who are particularly passionate about palliative care. Those who are less knowledgeable about palliative care may not have volunteered to participate in this study. Thus, the findings may not represent the perspectives of other care providers working in this field who are not particularly passionate or knowledgeable about palliative approaches to dementia care.

Finally, as a non-clinician I tried to represent as accurately as possible the current use and understanding of a palliative approach to dementia care in long-term care, but I may not fully appreciate the intricacies of provision of care.

Conclusion

As Canada's population ages, more people will die in long-term care. Due to population aging, the number of Canadians living with dementia is projected to reach 1.4 million by 2031 [5]. Dementia is a progressive condition and is a major contributing factor for transition into long-term care [72]. Currently, most persons living in long-term care in Canada have a form of cognitive impairment or diagnosis of dementia and in North America, most persons with dementia die in long-term care [11,66]. Therefore, a palliative approach that is appropriate for persons living with dementia is imperative now and in the future. The results of this study contribute knowledge to the study of palliative approaches in long-term care in a Canadian and dementia-specific context. Despite well reported challenges, the current study, like others in Canada [91,95], demonstrates that care providers recognize the benefit of palliative care principles for persons with dementia and want to provide a high-quality palliative approach to dementia care. Specifically, this study's findings demonstrate that while palliative principles are recognized as important for persons with dementia and components of a palliative approach are being used, there is a clear need for a shared understanding and integration of a palliative approach to dementia care in long-term care. Results from this study indicate the need to support health and social care providers to enable a higher quality provision of palliative and end-of-life care for persons with dementia and in the emotional labour of caring for persons with dementia who are dying. Caring for persons dying with/from dementia will increasingly become a part of care providers' roles in long-term care. It is critical they are provided adequate training, resources, and supports to provide a high-quality palliative approach to care and protect their own health and emotional well-being.

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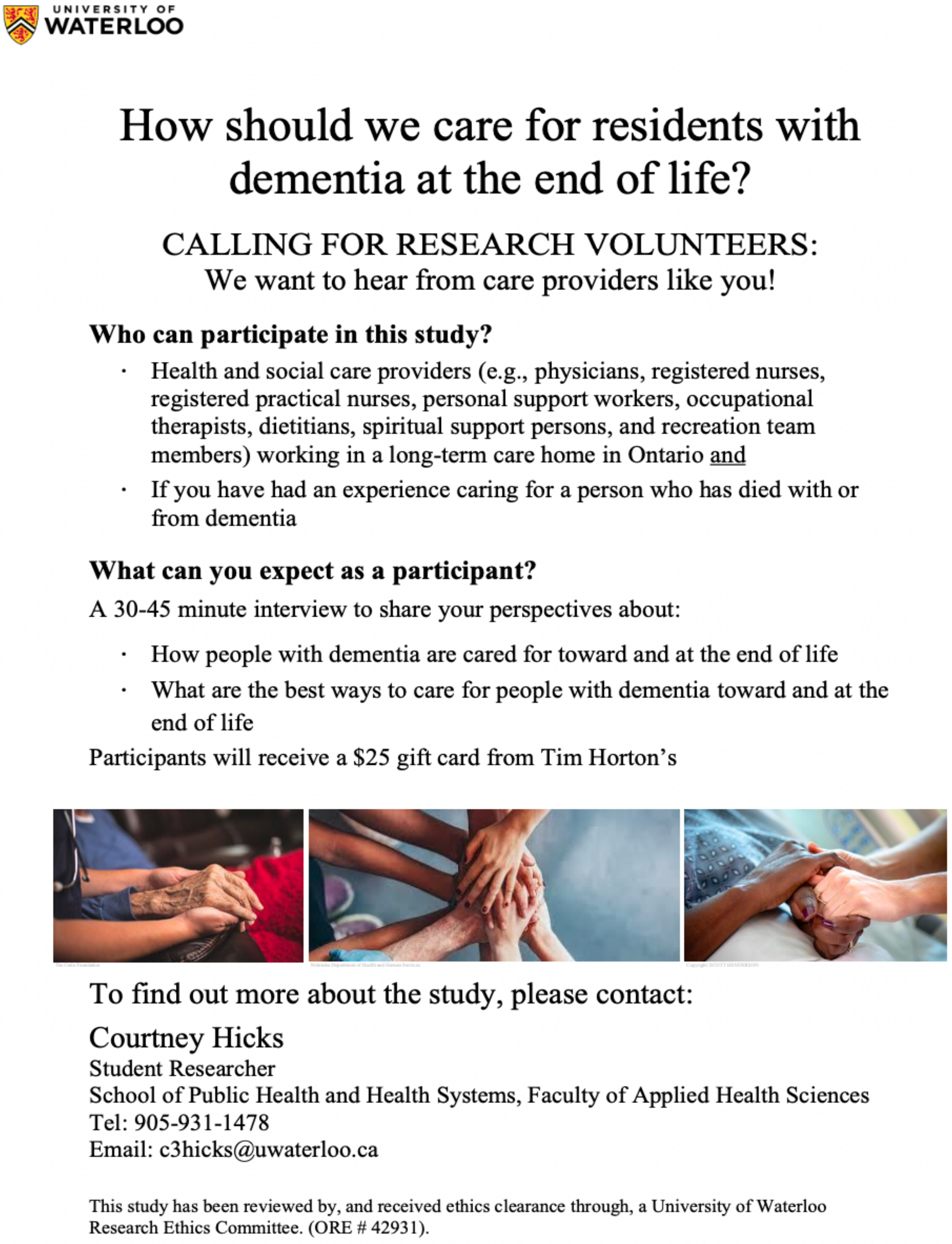
APPENDICES

APPENDIX A: Recruitment Poster



UNIVERSITY OF WATERLOO

How should we care for residents with dementia at the end of life?

CALLING FOR RESEARCH VOLUNTEERS:

We want to hear from care providers like you!

Who can participate in this study?

- Health and social care providers (e.g., physicians, registered nurses, registered practical nurses, personal support workers, occupational therapists, dietitians, spiritual support persons, and recreation team members) working in a long-term care home in Ontario and
- If you have had an experience caring for a person who has died with or from dementia

What can you expect as a participant?

A 30-45 minute interview to share your perspectives about:

- How people with dementia are cared for toward and at the end of life
- What are the best ways to care for people with dementia toward and at the end of life

Participants will receive a $25 gift card from Tim Horton's

Nebraska Department of Health and Human Services

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To find out more about the study, please contact:

Courtney Hicks
Student Researcher
School of Public Health and Health Systems, Faculty of Applied Health Sciences
Tel: 905-931-1478
Email: c3hicks@uwaterloo.ca

This study has been reviewed by, and received ethics clearance through, a University of Waterloo Research Ethics Committee. (ORE # 42931).

APPENDIX B: Research Information Sheet - Consent to Participate

RESEARCH INFORMATION SHEET and CONSENT TO PARTICIPATE IN RESEARCH

Research Study Title: A Palliative Approach to Care for People Living with Dementia: Exploring Perspectives from Health and Social Care Providers Working in Long-Term Care

Student Researcher, Department, Institution:

Courtney Hicks, School of Public Health and Health Systems, University of Waterloo

Supervisor, Department, Institution:

Carrie McAiney, School of Public Health and Health Systems, University of Waterloo

You are being asked to participate in a research study conducted by Courtney Hicks, a graduate student from the University of Waterloo. You are being invited to participate in this study because you are a team member working in long-term care and have cared for residents with dementia at the end of life. This study is being conducted as Courtney Hicks' master's thesis.

In order to decide whether or not you want to participate in this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study. Once you understand the study, and if you wish to participate, you will be asked to provide verbal consent by the researcher before the start of your interview. Please take your time to make your decision. Feel free to discuss it with others.

Your participation in this research study is voluntary.

What is the purpose of the study?

The overall goal of the study is to increase our understanding of how a palliative approach to care for people living with dementia is provided in long-term care. This will be accomplished through exploring the perspectives of health and social care providers working in long-term care. Specifically, this study will examine providers' perspectives on the use and optimal delivery of a palliative approach to care for people living with dementia. This research also seeks to explore the perceptions of health and social care providers about occupational roles in supporting a palliative approach to care for those with dementia.

Will I receive anything for participating in this study?

You will receive a $25.00 gift card as a token of appreciation for participating in an interview. The amount received is taxable. It is your responsibility to report this amount for income tax purposes.

What will happen if I take part in this research study?

Your participation in this research study is voluntary. If you agree to participate, you will be asked to participate in an individual interview that will last approximately 30-45 minutes. The interviews will be conducted virtually through a platform of your preference (e.g., Zoom, Skype, FaceTime) or by phone, at a time that is convenient for you. With your permission and verbal consent, these interviews will be audio-recorded and transcribed verbatim to ensure we are able to capture all of the information you share with us.

Approximately 15-20 participants will participate in individual interviews.

The following will be discussed during the interviews:

- Your role and experience in providing a palliative approach to care for people dying with/from dementia in long-term care
- Your perspective of what contributes to an optimal palliative approach to care for people with dementia in long-term care

Are there any potential risks or discomforts that I can expect from this study?

The risks to you are considered minimal; however, you may experience emotional discomfort during the interview since the questions may ask you to recall a time that was stressful or distressing. If you experience any feelings of discomfort, please let the researcher know. You can skip any question that you do not wish to answer in the interview. As well, you reserve the right to withdraw from the interview at any time by advising the researcher of this decision. Should you decide to withdraw, all audio recordings and transcripts will be destroyed.

Are there any potential benefits if I participate?

We cannot promise any personal benefits to you from your participation in this study. However, learning about your experiences in providing care to someone who is dying with/from dementia can benefit the individuals with dementia as well as current and future health and social care providers working in long-term care homes by increasing our understanding of what constitutes an optimal palliative approach in dementia care.

What are the potential costs of participation?

There are no costs to participate.

Will information about me and my participation be kept confidential?

Any information that is obtained in connection with this study and that can identify you will remain confidential. Your name will not be used at all in the study records. Any identifying information will be removed from the data that is collected and stored separately. Audio-recordings will be transcribed by the researcher and once transcribed and confirmed for accuracy, will be destroyed within two years of being recorded. Paper copies of study materials and data collected will be shredded once they have been transcribed electronically, within two years of being collected.

All electronic copies of study materials and data collected from you will be kept for a minimum of 7 years on a secure, password protected data storage system in the Faculty of Applied Health Sciences at the University of Waterloo. Your name will not be included in any presentations or publications resulting from this study; however, with your permission anonymous quotations from your interview guide may be used. If permission is given to use anonymous quotations, please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. Only researchers associated with this study will have access to study records. All records will be destroyed according to University of Waterloo policy.

A list of names and preferred contact information of participants will be kept in a secure file so that a summary of the results of the study can be sent to you.

If you participate virtually (e.g., Zoom, Skype, FaceTime), when information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.

PARTICIPATION IS VOLUNTARY

You have rights as a research participant, and by participating in this study you do not give up those rights. Participation in this research is entirely voluntary. You may refuse to answer any questions that you do not want to answer and still remain in the study. You can decide to end your participation in the research at any time, and still receive the gift card.

If you wish to withdraw consent to participate at any time, please contact Courtney Hicks at c3hicks@uwaterloo.ca. You do not need to provide a reason. If you decide to end your participation in the study, your data can be destroyed but this cannot be guaranteed if data analysis has already begun. Data analysis will approximately begin one week after you have participated. The researchers will aim to permanently delete your data within 2 weeks of withdrawing.

You will be informed in a timely manner if new information becomes available that may affect your willingness to participate.

How will I find out about the findings from this study?

The results of the study will be provided via a letter thanking you for your involvement and a Summary Report that will be sent to all study participants upon completion of the study.

Who can I contact if I have questions about this research study?

If you have any questions, comments, or concerns about the research, please contact:

Courtney Hicks
Student Researcher
School of Public Health and Health Systems, University of Waterloo
Email: c3hicks@uwaterloo.ca
Tel: (905) 931-1478

Or

Dr. Carrie McAiney
Faculty Supervisor
School of Public Health and Health Systems, University of Waterloo
Email: carrie.mcainey@uwaterloo.ca
Tel. 519-888-4567, ext. 45642

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 42931). If you have questions for the Committee, contact the University of Waterloo Office of Research Ethics at 1-519-888-4567 ext. 36005.

CONSENT STATEMENT: Verbal/Implied Consent

Research Study Title: A Palliative Approach to Care for People Living with Dementia: Exploring Perspectives from Health and Social Care Providers Working in Long-Term Care

Investigators, Department, Institution:

Courtney Hicks, School of Public Health and Health Systems, University of Waterloo
Tel. 905-931-1478; email: c3hicks@uwaterloo.ca

Carrie McAiney, School of Public Health and Health Systems, University of Waterloo
Tel. 519-888-4567, ext. 45642; email: carrie.mcainey@uwaterloo.ca

You will be given a copy of this information to keep for your records.

By continuing with the interview, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

Participant

I have read the information presented in the information letter about a study conducted by Courtney Hicks at the University of Waterloo. I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I am aware that I may withdraw from the study without penalty at any time by advising the researchers of this decision.

I consent to the following:

- To participate in a phone/virtual interview
- To having the interview audio-recorded to ensure accurate transcription
- To use anonymous quotations in any presentation or publication that comes from this research

I understand that participation is voluntary, and that I may withdraw from this study without affecting in any way my employment status.

I was given a copy of the signed consent form.

When this study is completed, we will write a summary of the results.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 42931). If you have questions for the Committee, contact the University of Waterloo Office of Research Ethics at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

APPENDIX C: Interview Guide

This interview is part of my master's thesis at the University of Waterloo's School of Public Health and Health Systems in Waterloo, Ontario. I'm working under the supervision of Dr. Carrie McAiney of the University of Waterloo's School of Public Health and Health Systems. I've prepared a few questions for this interview, which ask about your experience providing care to people with dementia, toward and at end of life and your perspective on an optimal palliative approach to care for those with dementia. I may ask some other questions to understand your experiences better. There are no good or bad answers, we just want to understand your experiences.

[If the Research Information Sheet was provided in advance]

Have you had time to read the Research Information Sheet I sent you?

[If yes]

Great, then I would like to take a moment to review some main points from the Research Information Sheet before we continue. [Review the highlights of the Research Information Sheet, include risks and what will happen with their data, confirm the important points about voluntary participation and withdrawal listed below]

[If no, proceed to go through the full Research Information Sheet]

By continuing with the interview, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

Confirm the following to the participant:

- Your participation in this study is voluntary
- The interview will last approximately 30-45 minutes
- If you do not want to answer some of the questions you do not have to, but you can still be in the study
- You can decide to stop at any time, even part-way through the interview for whatever reason
- If you decide to stop during the interview, we will ask you how you would like us to handle the data collected up to that point, whether returning it to you, destroying it or using the data collected up to that point
- If you participate in an interview, you will receive a $25 Tim Horton's gift card in appreciation of your time
- This study has been reviewed and cleared by the University of Waterloo Office of Research Ethics

Do you have any questions or want me to go over any study details again?

Consent questions:
Do you agree to participate in this study?

[If yes]

- Would you like a summary of the study results? If yes, where should we send them (email, mailing address)?
- Do you agree to the interview being audio-recorded to ensure accurate transcription?
- Do you agree to use anonymous quotations in any presentation or publication that comes from this research?

[If no]

Thank you for your time.

NOTE: As this is a semi-structured interview guide, adjustments were made as needed based on the conversations with the study participants. The guide below is comprehensive, although all lines of questioning followed the same topics as outlined here.

Interview questions and prompts:

1. Could you tell me about your position in long-term care?

    - Can you describe what your role is with residents who have dementia?
    - Can you describe some of the experiences you have had in your role caring for one of your residents with dementia who is palliative?

        - *Prompts*: How do you support them? What kind of tasks do you do? What supports you in providing this care?

2. From your perspective, what are your main goals of providing care to someone who has dementia?

    - Is it the same for everyone? How do you make decisions tailored to an individual?
    - How does the care change over time and approaching end-of-life? At what points are the goals of care reviewed for someone with dementia?
    - From your experience, do you feel supported in providing these goals of care for someone living with dementia? Why or why not?

3. Do you support the families and care partner of persons with dementia in your role?

    - (**If yes**) Can you tell me about an experience you had in supporting a family or care partner? After their loved one with dementia has passed away?

4. How is a person with dementia engaged about their future and end of life care?

Prompt: Values/wishes/preferences/beliefs?

- (**If persons with dementia are said to be engaged)** Does engaging the person with dementia about their future and end of life care change throughout their stay in long-term care?
- (**If persons with dementia are said not to be engaged**) From your perspective, could you speak to why?

5. Thinking about a time you provided care for someone with dementia, were you involved in the facilitation of a discussion around their preferences for future and end-of-life care?

    - (**If yes)** Could you walk me through your approach to these conversations?
    - (**If yes)** What prompted the conversations about future and end-of-life care? Who else was involved in these conversations? (e.g., staff, family)

    - (**If no**) From your perspective, whose role is it to have conversations with resident's and family around future and end-of-life care?

6. Thinking about a person with dementia you cared for who has passed away or a person you are currently caring for with dementia who is dying, can you tell me about how it was it determined that they were close to end of life?

    - Is this different for a person with dementia specifically? If so, how?
    - From your experience, when is a person living with dementia considered to be palliative? What prompts them to be considered palliative and when this occurs, does their care change? If so, how?

7. Thinking back to an experience caring for someone with dementia, can you tell me about how care providers collaborated with one another in providing their care?

    - How do you feel about the nature of collaboration in providing care for a resident with dementia toward and at end of life? What have been some positive experiences? What have been some negative experiences?

      Prompts: Communication between providers, information sharing, supporting each other, roles involved in supporting a palliative approach for persons with dementia

8. What do you feel about your knowledge base around a palliative approach to care for those living with dementia?

    Prompts: Education, training

- Do you feel supported to provide a palliative approach to care for persons living with dementia?
- Are there any areas where you feel you could benefit from more knowledge or support to help you provide a palliative approach to care for people with dementia?

9. If you could design the best care experience for a person with dementia in long-term care within a palliative approach, leading up to and including end-of-life, what would it look like?

    - How would you see yourself contributing?

10. Has the COVID-19 pandemic impacted the care and support provided to people with dementia in long-term care, toward and at end-of-life? If so, how?

Is there anything else you would like to add?

Participant demographic questions:

I have some final questions for demographic purposes. These questions will help us to describe the study sample. Could you please indicate which categories you belong to for the following questions?

What is your age?
    Under 30
    30-39
    40-49
    50-59
    Over 60

What is your gender?
    Woman
    Man
    Other

What are your ethnic, racial, or cultural origins?
    Black
    Chinese
    Filipino
    White
    Indigenous – specify
    Japanese
    Korean
    South American
    South Asian (e.g., East Indian, Pakistani, Sri Lankan …)

Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai …)
West Asian (e.g., Iranian, Afghan …)
Other

Thank you for taking the time to share your perspectives and experiences with me.

Talking about death and dying is difficult. If you need to speak with someone about your feelings or concerns, please reach out to your family doctor, another health care provider, or someone in your support system.

APPENDIX D: Thank-You Letter

[date]
Dear [name]:

Thank you for your participation in the '*A Palliative Approach to Care for People Living with Dementia: Exploring Perspectives from Health and Social Care Providers Working in Long-Term Care'* research study.

As a reminder, the purpose of this study is to understand a palliative approach to care for people with dementia living in long-term care. This is achieved through exploring the perspectives of health and social care providers in their experience providing care to people dying with/from dementia.

We want to remind you that your identity in connection with any information you shared with us about your experiences will be kept confidential. Your name will not be included in any presentations or publications resulting from this study. However, if you provided permission during your verbal consent, anonymous quotations from your interviews may be used.

Once all the data are collected and analyzed, a summary will be shared with you via email.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#X 42931). If you have questions for the Committee, contact the Office of Research Ethics, at 1-519- 888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

Again, thank you for your contribution to this study. If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact us and we would be happy to assist you.

Sincerely,

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