Navigating the Nutrition Information Landscape for Healthcare Providers of Residents in Long-Term Care Homes at the End of Life

by

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Abstract

Introduction: End of life (EOL) care is provided to residents in long-term care (LTC) homes and aims to support quality of life until death. EOL care does not always meet the expectations of caregivers as they often receive inconsistent and inadequate information about the resident's care at EOL. Issues of short-staffing and lack of EOL nutritional practices in LTC have been further accentuated by COVID-19.

Objectives: The objectives of this study were to examine 1) How healthcare providers (HCPs) perceive food and eating at the end of life for older adults in LTC in normal conditions and during a pandemic; and 2) What EOL nutrition conversations in LTC currently look like.

Methods: Sixteen HCPs working in Manitoba LTC homes were recruited and interviewed [female (88%), mean age ± SD = 42 ± 10.2 years; dietitians (62.5%)]. The semi-structured interviews were audio-recorded, transcribed verbatim, and analyzed using inductive content analysis.

Results: Three themes emerged from the interviews. 1) Negotiating tensions in nutrition at EOL: tensions arise from differing expectations and the importance of nutrition of the HCPs, caregivers, and sometimes the residents. HCPs provide education to caregivers on the role of food at EOL and what is best for the comfort of the resident. 2) Bridging the nutritional divide: EOL nutrition information is provided by HCPs to caregivers mostly through in-person conversations. HCPs stated that the most appropriate time to initiate these conversations is at admission or when there is a change in the resident's condition. 3) Challenges during COVID-19: visitor restrictions limited conversations to be over the phone and HCPs had to provide more frequent updates to bridge this gap. Due to the rapid progression of the virus, conversations about the nutritional care of COVID-19-positive residents involved more discussion of management of gastrointestinal issues and predicting health trajectory.

Conclusion: HCPs in LTC navigate tensions at EOL through balancing comfort and nutritional needs of the resident, and bridge the nutritional divide by providing education to caregivers. The COVID-19 pandemic affected the way EOL nutritional conversations were carried out due to visitor restrictions and the rapid progression of the virus.

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Dedication

To Baba and Gigi Pidborchynski, and Baba Pronyk for cheering me on, and to Gido Pronyk, for cheering me on from above. Дуже дякую

To Jake, my little Bichon boy. Thank you for bringing so much sunshine to my life during your 16 years on Earth.

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List of Abbreviations

ACP	Advance Care Planning
ANH	Artificial Nutrition and Hydration
EOL	End of Life
HCP	Healthcare Provider
LTC	Long-Term Care
QOL	Quality of Life
THC	Theory of Holistic Comfort
VSED	Voluntarily Stopping Eating and Drinking

CHAPTER 1: INTRODUCTION

Overview

In Canada, the proportion of individuals 65 years of age and older is approximately 19% (Statistics Canada, 2022) and this number is projected to increase. Seven percent of older Canadians live in collective dwellings that provides medical care, such as nursing or long-term care (LTC) homes (Statistics Canada, 2016). Of the residents living in LTC, 6.4% are under the age of 65 (Canadian Institute for Health Information, 2020b). Younger adults with intellectual or developmental disabilities may be admitted into LTC as their care needs cannot be met in the community. This has led to the discussion of the appropriateness of LTC for these individuals as it may not support their social needs as well as the fact that LTC is designed to support those in their last years of life (Canadian Healthcare Association, 2009; Ouellette-Kuntz et al., 2017). For this study, the focus will be on older adults (65 years and older).

Older adults are being admitted into LTC requiring more specialized care and with higher acuity (Canadian Medical Association, 2015). Hoben and colleagues (2019) identified that care needs increased and length of stay in LTC decreased to 1.5 years. The dying trajectory of those with dementia and frailty, aging-related conditions (Alzheimer Society of Canada, 2020; Cardona-Morrell et al., 2017), is characterized by a gradual decrease in function over a longer period of time compared to the trajectory of more acute conditions such as cancer or organ system failure (Lynn, 2005). This slow gradual decline can make it difficult to determine when an individual is expected to die (Hall et al., 2021). In residents with other chronic illnesses, it can be difficult to identify when they are close to death as some appear to be stable then unexpectedly die in their sleep, while others may live with the condition for years before death (Bern-Klug, 2009).

A palliative approach to care for residents living in LTC homes ensures that palliative care, defined as the aim to improve the quality of life of residents facing a life-limiting illness and their caregivers (World Health Organization, 2020), is available at appropriate times throughout the illness trajectory. It supports open communication regarding the wishes of the resident and caregivers about care, and provides psychosocial and spiritual support (Beacon, 2013; Kristjanson et al., 2003). End of life (EOL) care is a part of a palliative approach and typically encompasses care in the final months, weeks, or days of life (Hui et al., 2014). There is

much conceptual confusion surrounding the definitions of EOL and palliative care in the literature, and they are often used interchangeably (Izumi et al., 2012). Within this study, the term EOL will be used to describe the care provided to all residents in LTC from the time of admission until their death. This definition of EOL arose from discussions with current care providers and a review of the literature, which articulates the challenges of determining when older adults in LTC are nearing death due to the heterogeneity of symptoms and varying perspectives of HCPs (Fisher et al., 2000; Froggatt & Payne, 2006). In the final year or two of a resident's life, they themselves, their caregivers, and HCPs are aware of life-limiting condition(s) (European Association for Palliative Care, 2009), such as frailty, dementia, or cancer. In this context, EOL care takes a palliative approach and supports discussion of resident needs. A palliative approach in LTC has been shown to reduce hospitalization, improves communication between HCPs and caregivers, and has been received positively by residents and their caregivers (Kaasalainen et al., 2020). This definition of EOL will only be applied to older adults living in LTC.

Prior to the COVID-19 pandemic, EOL care was not meeting the expectations of caregivers of residents in LTC homes (Thompson et al., 2012). Issues identified by caregivers include receiving confusing information about the medical condition of the resident, communication issues, and the use of treatment inconsistent with the residents' wishes. Many of these issues were amplified on March 11, 2020 when the World Health Organization declared a pandemic (WHO - World Health Organization, 2020). LTC was one of the sectors affected the most, accounting for more than 80% of all COVID-19 deaths in Canada between March and May 2020 (Canadian Institute for Health Information, 2020a). As noted even before the pandemic, EOL of residents in LTC homes consisted of inconsistent and poor timing of messaging, lack of communication with family members/substitute decision-makers, and inconsistent practices by health care providers. With restrictions in LTC homes, caregivers were often not allowed to visit unless for compassionate reasons when the resident was considered to be actively dying. Some residents were only willing to eat in the presence of a caregiver so these visitor restrictions may have contributed to reduced oral intake (Shum et al., 2020), and meeting the nutritional needs of residents in LTC suffered. Issues related to EOL nutrition occurred including dehydration and malnutrition due to staff shortages, and inappropriate diet orders which increased the risk of choking (Mialkowski, 2020). The first vaccines for COVID-19 were approved in Canada in

December 2020, and vaccines were first given to HCPs (Government of Manitoba, n.d.-b, 2020b). Manitoba reported that the first dose for LTC residents was completed January 30, 2021 (National Institute on Ageing, 2021). As the eligibility criteria further changed to include the general public, visitor restrictions loosened to allow for more in-person contact through caregivers, which positively impacted quality of EOL care (Sinding et al., 2022).

Eating is a fundamental human activity. Not only is food essential to sustain our bodies, but it also holds great cultural, social, symbolic, and emotional significance. The meaning of food often changes at EOL as one often develops conditions that alter taste, swallowing, and decreased pleasure in food (McQuestion et al., 2011). Making decisions about EOL nutrition is complex as residents, caregivers, and health care providers (HCP) may have different opinions. Delay and/or avoidance of initiating EOL dialogue by the HCP with caregivers may also occur due to the uncomfortable nature of death and dying.

Current literature on food and nutrition in EOL care focuses on the implications of the administration or withdrawal of artificial nutrition and hydration (ANH) or its use in advanced dementia. Complications of ANH include catheter site infection, sepsis (Winter, 2000), and does not lead to significant improvements in thirst or delirium (Bear et al., 2017). There is limited research on the food and nutrition perceptions of older adults (regardless of cognition) at the EOL who are able to orally consume food (Hughes & Neal, 2000).

As we are aware, there are no research studies examining nutrition and EOL conversations and perspectives in LTC, even though there is evidence of challenges and inconsistencies.

Research Objectives

Study research objectives and corresponding research questions for each are as follows:

1. Examine the food and eating perspectives of HCPs of residents at the EOL in Manitoba LTC homes to determine the best information to guide EOL conversations in normal conditions and during a pandemic.
    a. How do HCPs perceive food and eating at the end of life for older adults in LTC?
    b. What is the current process for delivering EOL nutrition conversations?
    c. What impact has COVID-19 had on EOL conversations in LTC homes?
2. Determine when nutrition EOL information would be the most beneficial, and what are the most effective delivery methods once the resident is admitted into a LTC setting.

a. What do EOL nutrition conversations in LTC currently look like?
b. What EOL nutrition information is beneficial for caregivers to support decision-making?
c. What are the most effective delivery methods for EOL nutrition information once the resident is admitted into an LTC setting?
d. When should EOL nutrition information be discussed with caregivers?

Significance of Research

This study is significant as the findings will contribute to knowledge on EOL nutrition practices and potential policy changes in LTC homes. In Manitoba, there are currently no consistent EOL protocols in LTC that applies a palliative care approach to residents from admission. The results will contribute to the development of training and education programs for HCPs, allowing for better team involvement in EOL conversations. Constructive and timely conversations will engage and empower both the resident and/or caregiver in meeting residents' wishes around dying with dignity.

Concerning COVID-19 and pandemic planning, the results of this study will guide how to approach EOL nutrition when the resident is in isolation and substitute decision-makers are not available to visit. Due to the rapid decline in health as shown with the current pandemic, it is important that the resident's wishes are documented earlier so they can be carried out.

Chapter Summary

This thesis contains the following chapters:

Chapter 2 provides a summary of the relevant literature.

Chapter 3 provides an overview of the study methodology.

Chapter 4 presents the manuscript titled "Navigating the Nutrition Information Landscape for Healthcare Providers of Residents in Long-Term Care Homes at the End of Life."

Chapter 5 presents the manuscript titled "The Impact of COVID-19 on End of Life Nutrition Conversations and Processes in Long-Term Care: Challenges and Strategies of Healthcare Providers."

Chapter 6 provides a general discussion of the study findings, strengths, limitations, implications, and take-away points.

CHAPTER 2: LITERATURE REVIEW

Long-Term Care

LTC facilities (also called Personal Care Homes or Nursing Homes) are dedicated to providing around-the-clock care of those who require it, and 24-hour care is provincially legislated for all residents. Services provided include laundry, assistance with activities of daily living, administration of medications, recreation/activities, and housekeeping. LTC facilities also provide nutritious meals and snacks, and a Registered Dietitian works with each resident to ensure that any special dietary needs are met (Long Term & Continuing Care Association of Manitoba, n.d.). The cost of these services are shared by Manitoba Health, Seniors and Active Living, and the LTC residents. Most of the service costs in LTC are covered by the provincial government and residents based on their income with a daily charge between $39.50 and $95.20 (Government of Manitoba, n.d.-a). In Manitoba, there are approximately 130 LTC homes, totalling just under 10,000 beds. (Long Term & Continuing Care Association of Manitoba, n.d.). When looking at ownership of these homes, 57% are publicly-owned, 14% are owned by private for-profit organizations, and 29% are owned by private not-for-profit organizations (Canadian Institute for Health Information, 2021).

LTC is one of the most regulated industries in the country. They must be regulated and must be licensed if privately-owned, and there are pre-existing standards and guidelines for publicly-owned facilities to follow. The standards and guidelines are very prescriptive and involve extensive resources in creating them. Because of all the work that goes into them, it can be difficult to continuously improve them (Canadian Medical Association, 2015).

Demographics

The aging of baby boomers (those born between 1946 and 1965) combined with the increasing life expectancy has contributed to a rapid increase in the population of older adults (Carriere et al., 2007; Statistics Canada, 2011). In Canada, 18.98% of the population is over the age of 65 years (Statistics Canada, 2022). Of the population of older adults, 7.0% of them live in a LTC home (Statistics Canada, 2016). The need for LTC is predicted to increase by 59.5% in 2031 (Deloitte & Canadian Medical Association, 2021).

Looking more specifically at Manitoba, the average age of residents is 85 years, and those above this age make up 58.1% of the LTC population. Because females live, on average, four years longer than men (Statistics Canada, 2019), it is expected that the majority of residents

are female, making up 68.9% of the residents in Manitoba LTC homes (Canadian Institute for Health Information, 2020b). Almost half of the residents are admitted directly from inpatient acute care whereas only 19.6% of residents are admitted from their own homes.

Of the residents living in LTC, 6.4% are under the age of 65 (Canadian Institute for Health Information, 2020b). Younger adults with intellectual or developmental disabilities may be admitted into LTC as their care needs cannot be met in the community. This has led to the discussion of the appropriateness of LTC for these individuals as it may not support their social needs as well as the fact that LTC is designed to support those in their last years of life (Canadian Healthcare Association, 2009; Ouellette-Kuntz et al., 2017).

Level of Care and Length of Stay

Most provinces in Canada are seeking cutbacks on beds in LTC due to the cost of maintaining them combined with the fact that most older adults prefer to live in other settings (Canadian Medical Association, 2015). In 2017, the Winnipeg Regional Health Authority introduced the Priority Home program as a way to allow older adults to age in their homes longer rather than entering LTC by providing 90 days of intensive at-home care (Winnipeg Regional Health Authority, 2018). Services available include intensive case coordination, healthcare aides, rehabilitation services, and other home care supports. Although this program lessens the burden on hospitals, the consequences are felt by LTC. Older adults are arriving in LTC frail and with increased medical complexity and acuity, requiring specialized care. As the population of older adults grows, long-term care facilities are finding they lack the services and resources to manage the increasing acuity of their residents (Canadian Medical Association, 2015). This is now regarded as the new normal in LTC, but organization, design, and funding have yet to adapt to this change (Banerjee & Rewegan, 2016)

Overall, the length of stay of residents in LTC has been decreasing in Canada (Hoben et al., 2019). Most residents die in LTC (78.3%) with remaining 21.7% being transferred into a hospital, another residential care home, or into a home (Canadian Institute for Health Information, 2020b). The average length of stay was found to be approximately 1.5 years (Hoben et al., 2019).

Staffing and Standards

LTC homes require a designated registered nurse or registered psychiatric nurse to be in charge of the provision of services within the facility and a physician that is responsible for the

supervision of medical services provided to residents (Personal Care Homes Standards Regulation, 2017). Other employees in LTC providing direct care to residents include healthcare aides and licensed practical nurses (CUPE Manitoba, 2015).

The level of staffing in LTC is currently enforced through the *Personal Care Home Staffing Guidelines*, which requires facilities to provide 3.6 hours per resident day (Government of Manitoba, 2020a). This level of care is much lower than what experts recommended as a minimum, being 4.1 hours per resident day. Low staffing levels are associated with increased resident falls, lack of communication regarding care, and rushed care and meals (Manitoba Nurses Union, 2018). When care aides only have to focus on two or three residents at mealtimes, it decreases the risk of undernutrition, choking, and coughing. Understaffing has been an issue for years, as highlighted in a 2015 report by CUPE Manitoba. Manitoba does not have specific requirements for the level of staff in facilities, despite advocacy through HCP unions and workers themselves (CUPE Manitoba, 2015). Up to 60% of staff in Canadian LTC homes say that their workloads are too heavy for the time given, making it difficult to provide quality care. Many say that the reason for being short-staffed is that vacancies are not filled to save resources such as money (Banerjee et al., 2012).

As outlined under the *Health Services Insurance Act*, residents are to be given meals and snacks that are flavourful and appetizing in a way that meets the nutritional, personal, and therapeutic needs of each. The meals are to be served in a group dining environment to facilitate the social aspects of dining. Any resident requiring assistance should be provided so in a manner that promotes dignity and safety. A registered dietitian must also be available for consultation if needed, but in Manitoba there is no minimum amount of time that is enforced (Personal Care Homes Standards Regulation, 2017). In Ontario, dietitians are required to provide 30 minutes a month with each resident (Long-Term Care Homes Act, 2007), but this has been found to not be enough time (Dietitians of Canada, 2016).

Dietitians in LTC can have a range of duties, including menu planning, meal service, quality improvement, and nutrition and hydration care. Direct patient care involves consulting with the other staff, resident, and substitute decision-makers to ensure that nutrition interventions will meet the needs of the resident. Upon admission, the resident is assessed for any texture/fluid modifications, relevant diagnoses, the ability to feed oneself, swallowing concerns, and more.

From this, an individualized nutrition and hydration care plan is put into place (Ontario Long Term Care Action Group, 2019).

Common Diagnoses in Long-Term Care

Within LTC homes, a range of diagnoses with nutritional implications is observed. Diseases such as Parkinson's Disease, diabetes, renal insufficiency, chronic obstructive pulmonary disease, congestive heart failure, and dementia continue to rise (Van Rensbergen & Nawrot, 2010). In Manitoba LTC homes, 59.8% of residents have some form of dementia (Canadian Institute for Health Information, 2020b). And while everyone's journey is different, common issues related to nutrition include decreased appetite, swallowing impairments (dysphagia), and weight loss that leads to EOL (Alzheimer's Association of Canada, 2016). Up to 50% of older adults and 50% of those with a neurological condition have oropharyngeal dysphagia. This condition itself has its own implications including aspiration, severe nutritional complications, and high mortality rates (Clavé & Shaker, 2015). Nutritional interventions for a resident with dysphagia involves modification of food texture and fluid consistency, or ANH if oral feeding is not tolerated (Dietitians of Canada, 2015).

Cardiovascular conditions are very common in LTC, with 71.5% of residents in Manitoba being diagnosed with one. Hypertension is the most common condition in this category, as 57.4% of residents have it (Canadian Institute for Health Information, 2020b). Dietary management of hypertension often employs the DASH (Dietary Approaches to Stop Hypertension) diet, which is rich in fruits, vegetables, and low-fat dairy products, and restrictions sodium, saturated fat, and total fat intake (Appel et al., 1997).

Diabetes affects 23.1% of the population in LTC (Canadian Institute for Health Information, 2020b). Management of diabetes is complex due to multimorbidity, dependency on caregivers, complications, and cognitive impairment (Pandya et al., 2020). Care of older adults with diabetes must take a different approach due to the heterogeneity in clinical presentation. Because those in LTC have a limited life expectancy, the focus is on improving QOL rather than glycemic control (Munshi et al., 2016).

The cumulative decline of an individual's physiological system is also known as frailty. It is progressive and mostly irreversible and leads to increased vulnerability to more adverse health outcomes (Cardona-Morrell et al., 2017; Chen et al., 2014). Frailty is associated with increased

mortality, hospitalization, and a decrease in their ability to carry out activities of daily living, decreasing QOL (Vermeiren et al., 2016).

Older adults are also more likely to have more than one chronic condition, known as multimorbidity. The prevalence of this increases along with age (Sakib et al., 2019). Because of multimorbidity commonly seen in older adults, their care often requires an interdisciplinary approach involving HCPs in different specialties (Vellani et al., 2021).

Determinants of Food Intake in LTC

In LTC homes, there are many levels of factors that determine intake of food. It has been found that age, number of eating challenges, and a pureed diet are negatively associated with energy intake (Keller et al., 2017a). Other issues that residents experience include the fact that they are typically only offered one dish and the food does not taste like it would if the resident had made it themselves. Mealtimes also feel rushed as employees are eager to clean up and move onto their next task (Odencrants et al., 2020). Restrictive menus are an additional cause for decreased intake and malnutrition, highlighting the importance of liberalized diets (Volkert et al., 2019). The effects of malnutrition that may arise from limited food choices of medical nutrition therapy is seen as a greater risk the benefits. A liberalized diet enhances intake and quality of life (Dietitians of Canada & Ontario LTC Action Group, 2019; Dorner et al., 2002). Texture modification, such as pureed or minced foods, are associated with malnutrition in LTC (Vucea et al., 2018). Other factors associated with low intake include age, eating challenges, and requiring eating assistance. A study examining intake in Canadian LTC homes found that based on self-reported assessment, 44% of residents were moderately or severely malnourished (Keller et al., 2017b). There has also been research carried out on the determinants of fluid intake, and findings suggest that increased age, cognitive impairments, eating challenges, and increased staff presence in dining room is negatively associated with fluid intake (Namasivayam-MacDonald et al., 2018).

The Meaning of Food

The literal definition of food is "material consisting essentially of protein, carbohydrate, and fat used in the body of an organism to sustain growth, repair, and vital processes and to furnish energy" (Merriam-Webster, n.d.-b), but food also holds great cultural, social, symbolic, and emotional meanings (McQuestion et al., 2011). In a study on the meaning of food and meals in LTC, three themes emerged from the resident interviews: meals as an activity and involving at

least two people, meals related to habits and traditions, and the lack of individual choice (Odencrants et al., 2020). Even if the food isn't anything out of the ordinary, participants said that being in the presence of others was enjoyable and something to look forward to each day. The loss of appetite or ability to eat may also be seen as a loss of control in their life. This feeling is further amplified when caregivers try to persuade the individual to eat (Hopkinson, 2007).

For caregivers, food is an emotional topic and the meaning behind provision of food to the care recipient in LTC is a common theme in the literature. Many caregivers feel that their role in food preparation and feeding is part of their identity, and they find their purpose in it. How someone eats is also seen as part of their identity, such as being a "big eater," and when one's eating patterns change, it can be distressing for their caregiver to witness the loss of their identity (Ellis, 2018; Smith et al., 2015; Taylor, 2016). Most consider the decreased oral intake of food associated with being at EOL as a significant issue, as many see food as a way to sustain life (McInerney, 1992; Raijmakers et al., 2013). The changes in eating of an individual can also cause strain on their caregiver's relationship with them. It can be disappointing for a carer to spend time making a meal only for the care recipient member not to eat it (Hopkinson, 2007).

The physical meaning of food is also an issue. Similar to the literal meaning of food as defined above, food is seen as a way to provide one with physical strength, energy, and preserves life (Raijmakers et al., 2013). Both patients and their caregivers see food as a way to prolong life and fight illness even when the patient is deemed palliative (Taylor, 2016).

Informal Caregivers

In 2018, it was measured that 25% of Canadians over the age of 15 had, in the past year, provided care to an individual with a long-term health condition, disability, or aging-related problems (Hango, 2020). Of this group, almost 12% of caregivers are over the age of 65 years, making them older adults themselves (Statistics Canada, 2012). When one thinks about who a caregiver is, they often picture a family member such as a daughter, spouse, or sibling but caregivers can also be a friend or neighbour (National Academies of Science Engineering and Medicine, 2016). Another term for these caregivers who are an essential part of the resident's care is "designated family caregiver" (Shared Health & Government of Manitoba, 2021).

When looking at the role of caregivers of residents in LTC, they typically are having to navigate the complicated healthcare system, and act as a substitute decision-maker or proxy, meaning that they are responsible for making decisions for a resident's care when they are no

longer able to do so themselves (The Health Care Directives Act, 1993). It can be stressful for them, and evidence has indicated that caregivers are at a higher risk of depression, anxiety, and chronic disease (National Academies of Science Engineering and Medicine, 2016). Inside the LTC facility, caregivers regularly participate in care through support of feeding, mobility, hygiene, communication, and providing connection (Shared Health & Government of Manitoba, 2021). It has also been found that caregiver involvement in the care of a resident in LTC is associated with detecting conditions such as respiratory problems, hypertension, skin integrity, and pain. This positive effect helps ensure that the residents are able to get treatment for these conditions, especially with the low staffing rates seen in LTC (Port, 2006).

Medical Ethics

Approaching ethical issues in healthcare such as withdrawal and administering medical treatment is based on the four aspects of biomedicine- justice, respect for autonomy, beneficence, and non-maleficence, which involves putting aside one's own beliefs. Justice is often synonymous with fairness, meaning that the HCP treats everyone they encounter as equals. Respect for autonomy is the obligation to obtain informed consent, communicate with others, and respecting the patient's wishes for care. Beneficence and non-maleficence can be considered together and are regarded as providing medical benefits (beneficence) to the patient while doing minimal harm (non-maleficence or "do no harm"). The benefits of treatment should outweigh the risks (Gillon, 1994). HCPs may face an ethical dilemma when their patient or caregiver requests treatment that is deemed unnecessary or inappropriate by the HCP. Specific issues at EOL include the use of CPR on frail residents and the administration of ANH, as will be discussed later. The choices and wishes of LTC residents and their caregivers need to be respected, but appropriate care should also be carried to ensure QOL (Gordon, 2002). This balance can be difficult to achieve and from it arises tension between a HCPs duty of beneficence and respecting autonomy. This is where it is important to consider beneficence not only in the physical context of the resident but also emotionally and culturally (Miles et al., 2016).

Ethics can also be seen in the bill of rights that each LTC home is required to have. The bill states that all residents are to be treated with respect in a way that promotes dignity, has the right to give or refuse consent regarding treatment, and are encouraged to exercise their freedom of choice (Personal Care Homes Standards Regulation, 2017).

End of Life Care in LTC

EOL care for older adults in LTC can be difficult to define as the term EOL care is often used interchangeably with palliative care. In addition, EOL care has not been clearly defined in the context of LTC. Palliative care is defined as an approach to care that improves QOL for patients living with a life-threatening illness and their caregivers (World Health Organization, 2020). A palliative approach for LTC ensures that the principles and values of palliative care is adapted to and available for older adults in LTC. It supports open communication regarding the wishes of the resident and their caregivers about care, in addition to providing psychosocial and spiritual support (Beacon, 2013; Kristjanson et al., 2003; Sawatzky et al., 2017). EOL care is typically defined as the care provided in the final months, weeks, or days of life, and is synonymous with terminal care (Hui et al., 2014). The dying trajectory of older adults is not predictable, making it difficult to define when a resident is at EOL and actively dying (Banerjee & Rewegan, 2016; Bern-Klug, 2009). This is especially true with frailty, which follows a slow and gradual decline (Hall et al., 2021). In residents with other chronic illnesses, it is also difficult to determine if they are actively dying as some may pass in their sleep unexpectedly while others live with their condition for years (Bern-Klug, 2009). Based on the challenge of determining when a resident is nearing death, in this study the term EOL will be used to describe the care provided to all residents from the time of admission until their death. In this context, not all residents are actively dying, but they are at EOL due to the expected decline in health (Bern-Klug, 2009). It takes a palliative approach to care, which has been shown to reduce hospitalizations, improves communication between HCPs and caregivers, increases caregiver involvement, and has been received positively (Kaasalainen et al., 2020).

Problems may arise when conversations surrounding EOL care are not brought up in a timely manner. In the literature, the lack of open communication between HCPs and caregivers is one of the biggest barriers to excellent EOL care and the improvement of this communication is seen as an area of EOL care that needs to be prioritized. Death is a sensitive topic and staff in LTC homes avoid acknowledging the fact that these homes are a place where death commonly occurs. They prefer to think of LTC homes as a place for the living (Cable-Williams & Wilson, 2017; Heyland et al., 2010). This general discomfort with death and dying can cause HCPs to discuss the condition of the resident in a subtle and indirect manner, not providing the essential information caregivers may need to make a decision (Sutherland et al., 2019). Another challenge

HCPs face is that they feel if they begin EOL discussions too early, it may come across as giving up on medical treatment (Patel et al., 2018).

Within the LTC home itself, residents are often not invited to discuss what care they perceive to be comfortable at EOL as this care is viewed as one that should only be discussed and put into place when someone is actively dying (Sussman, Kaasalainen, Mintzberg, et al., 2017). If a resident is not seen as dying, putting EOL care in place is viewed as inappropriate (Bern-Klug, 2009). The lack or delay of EOL conversations can lead to reduced satisfaction with care for both the patient and their caregivers (Fowler & Hammer, 2013). Families and caregivers of residents may also be uncomfortable with discussing dying and EOL preferences with the resident as well (Clarke & Seymour, 2010). The intersection of LTC and EOL care has not been thoroughly studied, but it is still known that EOL care is lacking (Huskamp et al., 2012; Kaasalainen et al., 2019). Only one in 20 older adults who died in LTC received palliative (EOL) care (Canadian Institute for Health Information, 2018a), highlighting the need for better integration of EOL care in this setting. Within the past few years, there has been research and pilot projects carried out on embedding palliative care in LTC, called Strengthening a Palliative Approach in Long-Term Care (SPA-LTC), which is an evidence-informed program developed to encourage meaningful EOL discussions and planning (Kaasalainen et al., 2020). It has proven to be beneficial and will continued to be implemented in Canadian LTC homes, but will need to be further studies with larger sample sizes.

Canada currently does not have a national palliative policy guiding practices at EOL, which is a major contributor to inconsistent practices (Fowler & Hammer, 2013; Miles et al., 2016). In Manitoba, there is no consistent provincial palliative care strategy, and each regional health authority develops their own program (Canadian Institute for Health Information, 2018a). Looking at the existing palliative care documents in Manitoba, they are lacking substantially compared to other provinces, and documents guiding EOL care in LTC specifically are infrequent (Hill et al., 2019).

There is also a lack of education on palliative and EOL care in medical schools (Canadian Medical Association, 2016). On average, less than half of all undergraduate and postgraduate trainees completed a clinical rotation in palliative care (Gagnon et al., 2020). HCPs working in LTC emphasize that they feel unprepared to provide excellent EOL care and discussing death with caregivers and residents (Banerjee & Rewegan, 2016). Dietitians working

in LTC may also feel unprepared, as a lack of exposure to this setting has been identified as an issue in new graduated entering practice (Brissette et al., 2014).

Dignity and the Good Death

Dignity is defined as "the quality or state of being worthy, honored, or esteemed" (Merriam-Webster, n.d.-a). HCPs in LTC often use it in the context that they want to ensure that residents live a dignified life until death, or a "good death," as loss of dignity is a concern in a majority of those at EOL (Brodtkorb et al., 2017; Oregon Public Health Division, 2014). Just as with EOL care, a good death is not only the absence of physical pain, but also addresses the environmental, psychological, and emotional aspects of dying (Miyashita et al., 2008). Regarding medical treatment such as ANH, a good death means that treatment is not used to prolong life and that the patient has control over the treatments they receive (Meier et al., 2016). Everyone may have a different definition of what they consider a good death, but common themes are being pain-free, satisfying final wishes, and operating at the highest level of functioning as possible (Fisher et al., 2000). Many LTC residents wish for a natural death, meaning that medical treatments are not used to prolong life. They have accepted the fact that they are dying and are ready to do so when they are meant to die and not receive treatment that will only allow them to live a few extra days or so (Bollig et al., 2016). Only 25% of caregivers believe that living for as long as possible is a value important to the resident (Siu et al., 2020). Another common theme is comfort, both physically and psychologically. Examples include not being thirsty, being at peace, and having the opportunity to discuss death (Meier et al., 2016; Takahashi et al., 2021).

Advance Care Planning

In Manitoba, the Health Care Directives Act allows anyone over the age of 16 to voluntarily express their wishes regarding healthcare they receive should they be unable to communicate this themselves when needed. The Act also allows the provision of power to another person to make medical decisions for the patient if they are unable to do so themselves, also known as a proxy. If the patient's wishes are not expressed, the proxy is to act on any wishes they know that the patient would have wanted (The Health Care Directives Act, 1993). Preparation for death through ACP has been found to help one achieve a good death as it allows one to exert control over the dying process (Meier et al., 2016; Munn et al., 2008). The prevalence of Canadian older adults who have discussed their EOL wishes is 66%, yet only 44%

of the population have a written document detailing their wishes (Canadian Institute for Health Information, 2018b). Reasons for LTC residents not having ACP documentation include lack of knowledge and interest, as well as the belief that family or HCPs should be the ones making the EOL decisions (Siu et al., 2020). Despite these barriers, older adults have expressed their desire to participate in EOL care planning and that they currently feel that it is carried out too late (Sharp et al., 2013). The frequency of LTC residents engaging in ACP across Canada is highly variable between provinces as well. Experts in EOL care are rarely involved in planning (Choi et al., 2020). ANH is one treatment that is included in this plan but is not discussed as often as other treatments such as hospital transfer, antibiotic use, and resuscitation. Artificial nutrition is only discussed half the time or less, and artificial hydration is discussed even less often (Siu et al., 2020).

Ideally, ACP should be started when the resident has little to no cognitive impairment, as with dementia their ability to make decisions is limited (Hirschman et al., 2006). Early planning should also be carried out because the dying trajectory is difficult to predict in frail older adults (Flo et al., 2016). Not discussing with the resident their wishes surrounding EOL nutrition earlier when the resident had little cognitive impairment was found to be a regret of caregivers (Miles et al., 2016). HCP can play a role as well in ACP by ensuring that residents know that they have options regarding care at EOL and offer opportunities to have these discussions (Bollig et al., 2016). Re-evaluation of resident wishes should be carried out periodically as preferences have been shown to change during their stay in LTC (McParland et al., 2003). In Manitoba, there are a number of resources available to individuals and their families as well as HCPs to support ACP (Advance Care Planning Canada, 2020).

Nutrition at the End of Life in LTC

The meaning of food changes when one develops a condition that affects taste, swallowing, and loss of pleasure in food (McQuestion et al., 2011). The goal no longer is maintaining optimal nutritional status, but rather meeting the needs of the resident, their family/friends, and ensuring comfort and QOL until the end. (Prevost & Grach, 2012). Management of diseases moves towards more holistic approach promoting comfort, managing symptoms, avoiding hospitalizations, and preserving dignity and QOL (Dunning, 2020; Munshi et al., 2016; Pandya et al., 2020). This approach to nutrition aligns with the palliative approach in that it not only addresses the physical needs of the resident, but also the psychological and

emotional needs of both the resident and their caregivers (Prevost & Grach, 2012; World Health Organization, 2020).

Communication within the healthcare team and with the resident and their caregivers is a major factor in determining EOL nutritional practices. Interdisciplinary teams need to openly and effectively communicate as they all have different backgrounds and knowledge (Miles et al., 2016; Sawatzky et al., 2017). This team then needs to relay information to the resident and their caregiver, sharing the options, risks, and benefits to allow for an informed decision. The timing of sharing this information is important, as those involved need time to make a decision that is not rushed (Miles et al., 2016). Dietitians may not be always present, therefore nutrition often becomes the responsibility of other HCPs, with nurses having a large role in the decision-making process around EOL nutrition as both the activator of these conversations as well as the mediator between the resident, caregiver(s), and other HCPs. This highlights the importance of EOL nutrition education for all (Acreman, 2009; Albanesi et al., 2020).

An issue that HCPs face when an individual is at EOL are the competing discourses involving prolonging life vs. maintaining a high QOL. Improving QOL has the potential to shorten life, or medical interventions to lengthen life could lead to a decreased QOL (Van Der Riet et al., 2009).

Approaches to nutritional support at EOL does not have a "one size fits all" method, and involved consultation with the resident, their caregiver, and HCPs (Yukawa & Ritchie, 2015). No one event defines when EOL care should begin, further highlighting the individuality of this approach (Druml et al., 2016). Expressed desire for care from the resident is what should guide interventions (Ontario Long Term Care Action Group, 2019).

The following discusses different options for providing nutrition at EOL, although some are not used as frequently as others.

Artificial Nutrition and Hydration

ANH is the provision of nutrients either through the enteral or peripheral route. (Casarett et al., 2005). Despite evidence indicating that ANH does not lead to better outcomes, it is still being used. Risks include infection at the insertion site, aspiration, fluid overload, and sepsis (Winter, 2000; Ying, 2015). In regard to artificial hydration on its own, there are benefits of forgoing its use as dehydration in the dying process is associated with decreased coughing, ascites, nausea, vomiting, and urine output (Ontario Long Term Care Action Group, 2019). ANH

is considered medical treatment, not basic care (Volkert et al., 2019). It is also important to note that even if ANH is stopped, maintaining the best QOL for the patient is still the goal of care (Druml et al., 2016).

When looking at the opinions of LTC residents on ANH at EOL, there is limited research but the existing literature shows that there is no one preferred intervention. In one study, the percentage of residents who would prefer long-term ANH was only 0.6% more than those who did not want ANH at EOL (Rahman et al., 2016). Another study, this one a follow-up study, showed similar results. It was observed that 23% of the population was given ANH until death, whereas 22% had ANH withheld (Penders et al., 2020). These two studies were done in the United States and Switzerland, respectively, where patient autonomy is strongly emphasized, similar to Canada.

In caregivers, many view ANH as basic medical care and are unaware of the risks associated with it. The resident's lack of interest in food can be distressing to them because of the meanings and importance they place on food and their roles in feeding, leading to the desire for nourishment through ANH (Del Río et al., 2012; Yukawa & Ritchie, 2015). Some may even feel that if they allow the resident to die of starvation rather than due to their declining health, they have failed them (Kaye et al., 2020). As mentioned above, there is evidence that ANH does not lead to better outcomes, yet many caregivers and patients are still choosing it in their care. This is why it is important that studies examining the perspective of residents and caregivers surrounding ANH is carried out (Baillie et al., 2018). It is recommended that if ANH is requested by the resident or their caregiver, that HCPs investigate the reasons for this wish and what they expect from the treatment (Orrevall, 2015).

When looking at the perspectives of HCPs towards ANH, many say that more research is needed to determine the nutritional needs of those at EOL and to identify markers that indicate when needs are changing (Baillie et al., 2018). ANH is also a source of moral and ethical dilemmas as withdrawing it often invokes feelings of leaving the patient without care and going against their professional mission (Albanesi et al., 2020). Because oral feeding is recommended over ANH for older adults, its use is low in LTC (Volkert et al., 2019), but it is still important to mention as it is a potential form of care one may request at EOL.

Comfort Feeding

Comfort feeding is an individualized and holistic approach and is the oral provision of food and drink to the resident only if they want it, and not forcing them to eat, and this should be continued for as long as it is safe to do so (Merlane & Cauwood, 2020; Miles et al., 2016; Yukawa & Ritchie, 2015). The foods offered should ideally be soft and easy to eat, such as ice cream, eggs, yogurt, and refreshing drinks. These meals may also stray away from what is normally offered to residents and instead are tailored to the personal preferences of the resident (Orrevall, 2015). With this approach, meeting the nutritional needs of the patient is forgone. Comfort feeding is the recommended method of feeding an older adult in the terminal phase of an illness over ANH (Volkert et al., 2019). The reasoning for this is that ANH is considered an intervention meant to prolong life and if this is not the goal, the patient's QOL should be the main focus. Comfort feeding is also associated with less discomfort compared to ANH. In a study in which terminally ill patients were offered any food and drink they wanted, it was found that almost two-thirds of them did not experience any hunger or thirst even when intake was inadequate (McCann, 1994). Any feelings of dry mouth or lips were easily resolved with ice chips, small amounts of fluid, or mouth care. In regard to comfort, 84% of the residents reported being comfortable in relation to their food and fluid intake.

As previously mentioned, up to 50% of older adults or those with a neurological condition such as dementia have swallowing difficulties (Clavé & Shaker, 2015). With this, there is the risk of aspiration pneumonia and death if oral feeding is continued, creating a situation in which making a decision is difficult. This is further amplified by the lack of education in HCPs, who state that they have received little training on "risk feeding" as this intervention is called (Miles et al., 2016)

Comfort feeding is included in the best practices for dietitians in LTC. At mealtimes, residents are to be slowly hand-fed using small amounts of food each time. If the resident shows shortness of breath or begins coughing, feeding is paused until they confirm that they are ready to eat again (Ontario Long Term Care Action Group, 2019).

Alternatives to Feeding

If a resident at EOL can no longer tolerate oral feedings and the use of ANH is futile, alternative means of human interaction can be used instead of feeding, such as simply speaking to them (Palecek et al., 2010). Therapeutic touch can also be used as an alternative to feeding. A

study by Kaye and colleagues discusses the use of essential fatty acids massaged into the patient's skin as a form of nourishment (Kaye et al., 2020). Studies have shown that topical application of essential fatty acids on the skin improves skin quality with no inherent risk (Skolnik et al., 1977). Although the nutritional benefits are minimal, it allows caregivers to show their love without the use of food and instead through touch (Kaye et al., 2020).

Competent individuals at EOL may choose to stop eating and drinking entirely, which is also known as voluntarily stopping eating and drinking (VSED). It is a morally challenging issue as it can be perceived as an alternative to physician-assisted suicide or euthanasia. In addition, caregivers experience distress as they believe that this is killing the person rather than letting them die, as well as concerns surrounding the symbolism of food (Bernat et al., 1993). There are varying opinions on whether or not VSED worsens or eases suffering. As the patient progresses with VSED, they often become delirious and frequently ask for a drink, as thirst is the most commonly reported symptom (Quill et al., 2018). Yet, it is believed that dehydration may have a benefit in providing analgesic effects to the patient through the production of ketones and opioids in the body (Printz, 1992).

A more controversial option is the use of stopping eating and drinking by advance directive, where a competent individual states in their ACP that if they get to a certain stage of dementia, they do not want to be provided with food or drink (Wright et al., 2019). This differs from VSED in that stopping eating and drinking by advance directive most always involves stopping the provision of food and drink to someone who may still be accepting them (Quill et al., 2018). With this advance directive, it is thought that there is no one choice that can be made without the HCP having to practice an injustice. If the HCP implements this process, it infringes on their responsibility of beneficence and nonmaleficence. But if they do not follow these orders, the family may see this as an injustice and violation of the autonomy of the patient. Because of this ethical dilemma, it is recommended that comfort feeding is put into place instead for those still accepting of food and drink (Wright et al., 2019).

Religion and EOL Nutritional Practices

One's perspective on EOL care, especially ANH, can be influenced by or based on the religion they follow, highlighting the importance of understanding resident's beliefs and religious practices. In the Roman Catholic faith, ANH is seen as basic care for those who cannot ingest food and fluid orally, but if it will not prolong life or cause significant discomfort, it is

then seen as optional. Any decisions that would lead to the hastening of death, such as VSED or stopping eating and drinking by advance directive, are seen as immoral. Proxies are to make decisions that do not go against Catholic teachings (Catholic Health Alliance of Canada, 2012). Similarly, Orthodox Christians deem the withdrawal of ANH unacceptable (Alberta Health Services, 2015). Protestants have very few restrictions for medical care and allow for withholding or withdrawing ANH (Bülow et al., 2008).

The beliefs in Judaism are similar to Catholicism, as ANH is to be provided as basic care unless it harms the patient. It is also forbidden to withdraw treatment that hastens death. ACP is allowed to be used, but the rabbi must be included as a proxy in order to ensure treatment aligns with Jewish law (Kinzbrunner, 2004). They also have guidelines surrounding oral feeding, as it is the responsibility of the child to ensure that their parent(s) in a LTC home are adequately fed and it is done so in a respectful way (Jotkowitz et al., 2005).

Individuals following the Islam religion are the most likely to oppose withholding or withdrawing ANH (Wolenberg et al., 2013). Allowing the patient to go without food is seen as starvation leading to death, a crime in Islam. ACP is not seen as legally binding, but individuals are permitted to request discontinuation of treatment if it does not improve QOL or causes harm, except for ANH (Ebrahim, 2000).

COVID-19 in Long Term Care and its Impact on Nutrition

Starting in 2020, COVID-19 has devastated LTC homes across the world. At the peak of the crisis in LTC in spring 2021, Manitoba reported over 100 outbreaks in LTC. More than 80% of deaths from COVID-19 were of Manitobans over the age of 65 years. (Government of Manitoba, 2021). Nationally, 81% of deaths from the virus were reported from LTC homes between March and May 2020, making Canada the country with the highest proportion of LTC deaths compared to other countries in the Organisation for Economic Co-operation and Development (Canadian Institute for Health Information, 2020a). Issues surrounding nutrition during the first wave of the pandemic includes inadequate food and fluid due to staff shortages and isolation, leading to weight loss, malnutrition, and death. Registered Dietitians were often not allowed to be on-site to monitor residents at a high risk for nutrition-related issues such as dysphagia. (Scaman et al., 2020). These first-wave issues were seen in Ontario and Quebec. In the media, a news article reported on an Ontario resident with advanced dementia who died of malnutrition and dehydration from lack of care (Glover, 2020). LTC facilities were suffering so

much that they requested additional assistance from the Canadian Armed Forces (Mialkowski, 2020), subsequently leading to the creating of a joint task force that put out a report highlighting the factors that led to such issues (Government of Canada, 2020).

Provinces that were not impacted as much during the first wave took note of what happened in Ontario and Quebec and developed policies and practices to prepare for subsequent waves, which including calling all families to discuss goals of care should their care recipient test positive or an outbreak occurs in the home (Di Sante et al., 2021). Unfortunately for some provinces, it was not enough as Manitoba began to experience a second wave that commenced approximately at the end of September 2020, and with it, more issues in LTC homes are coming to light in the media. The Government of Manitoba commissioned a review of the situation at one privately-owned LTC home to assess the situation, document the events, and provide recommendations on how to move forward (Stevenson, 2021), which became known as the Stevenson Review. To control the spread of the virus, residents were made to eat separately in their rooms, which they reported that they did not like. In normal conditions, family members often assisted with meals, but this was not able to continue once visitor restrictions were put in place. This led to staff concerns around the provision and management of food and drink. For some, the presence of a caregiver provides encouragement to eat, makes mealtimes more enjoyable, and can imitate the experience of eating at home (Muir & Linklater, 2011). In regard to communication with caregivers, many family members did not receive the level of specificity they would have wanted about the status of the resident, and many were concerned that they were not being cared for adequately (Stevenson, 2021). Numerous reports were seen in the media surrounding the issues in LTC, including one published November 2020 regarding the nutritional status of residents in a Winnipeg LTC home. One resident was reported to have been losing weight and others were dehydrated (Coubrough & Levasseur, 2020). Many conversations regarding care had to be carried out virtually (Unger, 2020).

The first vaccines for COVID-19 were approved in Canada in December 2020, and eligibility criteria for the vaccine began with HCPs (Government of Manitoba, n.d.-b, 2020b). Manitoba reported that the first dose for LTC residents was completed January 30, 2021 (National Institute on Ageing, 2021). As the eligibility criteria further changed to include the general public, visitor restrictions loosened to allow for more in-person contact.

On January 18th, 2022, the Department of Seniors and Long-term Care was created with the task of implementing all recommendations of the Stevenson Review (Government of Manitoba, 2022). This change occurred around the same time that LTC experienced large outbreaks during the fourth wave of COVID-19 that had begun Fall 2021. In January 2022, 34 of the 39 Winnipeg LTC homes had a declared outbreak (Winnipeg Regional Health Authority, 2022). Although the death rate for this wave was much less than previous ones, visitations were still limited, and significant staff shortages were apparent. In April 2022, $15 million was invested in LTC to implement the 17 recommendations of the review (Rosen, 2022).

The importance of ACP has been shown through the pandemic. In the report from the Canadian Armed Forces, it was found that preferred EOL care was not documented or was unknown to the staff, therefore it could not be put into place (Mialkowski, 2020). Regarding caregiver visitation at EOL, considerations for compassionate visits were made based on the resident's dying trajectory, where EOL was defined as the last two weeks of life (Shared Health & Government of Manitoba, 2021; Vellani et al., 2021). When looking at the documentation that was available to guide palliative care during COVID-19, it showed that although ACP is mentioned frequently, it lacks guidance on the process of communicating EOL treatment preferences (Gilissen et al., 2020). In addition, carrying out a palliative/EOL approach in LTC was found to be difficult during the pandemic as HCPs were often unable to support the family of the resident due to visitor restrictions (Di Sante et al., 2021).

Throughout the literature on COVID-19 in LTC, a common theme is the staff shortages. This is not a new issue, as inadequate staffing levels have been reported as a barrier to providing EOL care in LTC even before the pandemic (Brazil et al., 2006). Looking at the staffing situation in one Manitoba LTC facility during an outbreak, very rarely was there 100% of the regular staffing, and often the staffing dropped below 70%. General labourers had to be brought in from outside the home to provide nutrition and hydration support to residents (Stevenson, 2021). Other articles written about the COVID-19 situation in LTC focused on symptom management and care of those with dementia. What was not frequently found in the COVID-19 literature was discussion of what EOL conversations looked like, which suggests a lack of communication as discussed above regarding the Stevenson Report.

What has been learned so far from this experience is the importance of starting EOL conversations early and that they occur frequently (Shamon, 2021). In a study on EOL

perceptions of nurse practitioners, many stated that the pandemic highlighted the need to have discussions regarding care more often than on admission or when acute changes occur due to the rapid changes in health status seen in LTC (Vellani et al., 2021). It has been suggested that having ACP in place well before death can lessen the burden on caregivers (Parks & Howard, 2021).

Theoretical Framework

The theory of holistic comfort for nursing (THC) as proposed by Kolcaba in 1994 was used as a theoretical lens to shape the questions used data collection and analysis. A discussion of the use of THC is discussed in Chapter 6.

Comfort, in everyday use, can take on many definitions and can be a cause that produces comfort as an effect, further complicating the definition (Kolcaba, 1992). The definition used in THC is active, passive, or co-operative satisfaction of basic human needs for relief, ease, or transcendence arising from stressful health situations. The basic assumptions of this theory are that complex stimuli invoke a holistic response in humans, comfort is a desirable outcome, and that humans strive to have their basic comfort needs met. By addressing and enhancing one aspect of comfort, other aspects are indirectly enhanced as well. The first dimension involves relief, ease, and transcendence (Kolcaba, 1994). Relief is experienced when one's specific needs are met and is an important part of a peaceful death. Ease is the state of calmness and transcendence is a state in which ordinary powers are enhanced and designates the patient's potential for a good death (Kolcaba, 1991; Paterson & Zderad, 1976). The second dimension addresses the context in which care takes place, including physical, social, psychosocial, and environmental. The two dimensions are juxtaposed, and the three states of comfort occur in each of the four contexts (Kolcaba, 1992).

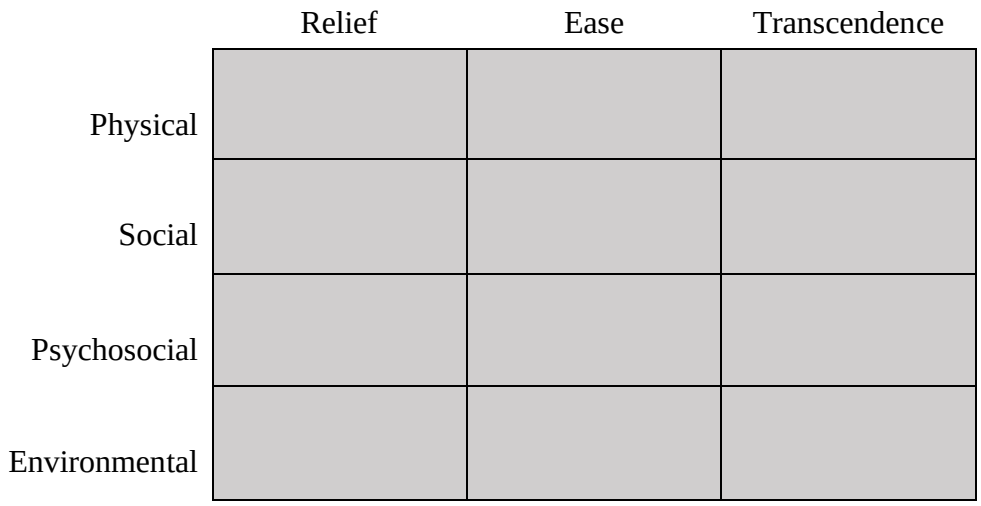

Figure 2.1. Kolcaba's Taxonomic Structure for Comfort Theory
(Kolcaba & Bice, 2021)This figure is available Open Access, and is being reused with the blanket permission of Dr. Kathy Kolcaba and Dr. April Bice found at https://www.thecomfortline.com (Kolcaba & Bice, 2021).

Comfort is important at EOL because it allows for acceptance and relief with death (Kolcaba, 1994). The THC aligns with a good death as it encourages proactive, thoughtful, and goal-oriented participation. These goals of care are ideally articulated by the patient or are included in ACP but if this is not feasible, decisions are made by a proxy. This framework of comfort can provide guidance in making EOL decisions (Kolcaba & Fisher, 1996).

Although this theory is commonly discussed in the context of care provided by nurses, it can be applied to institutions as a whole in that HCPs in other disciplines can use it in their own practices (March & McCormack, 2009).

It is also important that EOL discussions include all dimensions, as discussed previously, food has many more meanings than just physical. Unfortunately, this is likely not the case, as it has been documented that spiritual care workers, who would address needs in the psychosocial dimension, are only involved in EOL discussions at a low frequency (Choi et al., 2020). Because nutrition at EOL takes a more holistic approach, this theory will aid in helping describe the experience of HCPs interviewed. More information on how the THC was used to guide the methodological approach for this study is provided in Chapter 3.

Research Gaps

There is currently very little research that has been done to examine the perspectives surrounding EOL nutrition in LTC. Current literature on EOL nutrition in older adults mainly focuses on the administration or withdrawal of ANH, or the use of ANH in older adults with advanced dementia and lacks a focus on those in LTC. Much of this research has been done in Europe, and very little has examined the perceptions of Canadians. There is also very limited research on solely food and nutrition perceptions of those caring for older adults in LTC at EOL, as most of the current literature focuses only on pain management, hospitalizations, and resuscitation preferences. When looking at participants in studies examining EOL practices in LTC, many of the studies that discuss nutrition include very few to no dietitians, despite their expertise. When looking at the timing of and content included in EOL discussions with older adults and their caregivers, the current literature focuses on specific conditions such as cancer, dementia, or chronic pulmonary obstruction disease. Another issue is the inconsistent and interchangeable use of the terms EOL and palliative, making it difficult to determine if when each should be put into place and the differences between the two. More recently, COVID-19 has exposed a gap in the literature regarding EOL care and nutrition during pandemics. A majority of the current literature on the LTC experience with COVID-19 focuses on the care of residents with dementia only. Research on EOL centers around the management of COVID-19 symptoms such as shortness of breath or care of residents with dementia and does not include anything about nutrition conversations.

CHAPTER 3: METHODOLOGY

Study Population and Recruitment Procedures

For this qualitative cross-sectional study, HCPs employed in one or more LTC homes located in Manitoba were recruited and interviewed. Recruitment occurred through Winnipeg Regional Health Authority (WRHA) dietitians working in LTC, Manitoba members of Dietitians of Canada Gerontology Network, Manitoba Gerontological Nurses Association, Prairie Mountain Health, Southern Health, and other connections in Manitoba LTC homes. The study information (Appendix A) was emailed to the organizations to be shared with members, employing convenience and snowball sampling. Information was also shared during the WRHA LTC dietitian practice council. Inclusion criteria was that participants must: 1) have held a position working as an HCP in one or more LTC homes in Manitoba for at least the past two years starting in their position before the pandemic began (March 2020) so that participants would be able to provide insight on EOL nutrition conversations in normal times and during the pandemic; 2) participate in EOL discussions at their LTC home; and 3) able to carry out conversations in English. Interested participants could email the researcher for more information and to schedule the interview.

Interview Guide

The semi-structured interview guide (Appendix B) consisted of 23 questions: six demographic questions such as age, sex, occupation, and length of time working in LTC; two Likert scales to rate timing of and comfort with EOL nutrition conversations; two ranking questions where participants ranked five items in order of importance (one to five with one being most important and five being least important), and 13 open-ended questions assessing perceptions regarding nutrition and EOL conversations in LTC with residents and their caregivers. The impact of COVID-19 on EOL processes and conversations was also addressed in the open-ended questions. The questions for the interview guide were developed in consultation with my advisor and reviewing the literature on EOL. All questions were reviewed by the researchers and two experts in the field (a dietitian and an academic) for relevancy to the study objectives, flow, appropriateness, and comprehensibility for the research participants.

Data Collection Process

In-person interviews were originally planned for this study but due to COVID-19 provincial public health orders and the University of Manitoba ethics mandates, we were required to modify the way we collected data to prevent the spread of the virus to participants and researchers. Interviews were conducted over the telephone and audio recorded. Each interview took 30-60 minutes, and time was managed based on each participant's time restraints. The semi-structured interview guide allowed the researcher to ask clarification and probing questions to help gain a better understanding of the participants' experiences. Participants were given an opportunity at the end of the interview to provide any additional comments about EOL nutrition which they thought were important to add.

All interviews were confidential, and participants' information was identified only through a randomized numerical code in the transcripts. All participants were required to give written consent prior to their involvement in the study (Appendix C). Participants received a $25 grocery e-gift card after their interview compensating them for their time, except for those working in a specific health region where a policy mandated that they could not accept research incentives. If participants withdrew from the study at any time, they would be able to keep the gift card as long as they had previously signed the consent form.

As the sample size needed to reach saturation cannot be predicted *a priori* (Sim et al., 2018), interviews were continued until no new themes emerged in the transcripts, signalling that saturation was reached. Concurrent interviewing, transcription, and coding was completed as it allowed the researcher to see which topics were covered through the interviews for reliability and validity purposes (Morse et al., 2002).

Data Analysis

Descriptive data analysis was conducted for demographics, ranking, and Likert scale questions (means, standard deviations, frequency) using Microsoft Excel (Version 16.2, 2022). Table 3.1 shows the analyses completed for the demographic questions and Table 3.2 shows the analyses completed for the open-ended questions.

Table 3.1. Demographic data analysis summary

Healthcare Provider	**Analysis**
Year of birth (age)	Mean, standard deviation
Sex	Frequency
Occupation	Frequency
Years working in LTC	Mean, standard deviation
EFT	Mean, standard deviation
Health region	Frequency

Table 3.2. Data analysis summary of open-ended interview questions

1. How do caregivers and HCPs perceive food and eating at the end of life for older adults in LTC?	
Question	**Analysis**
Please rank these items in order of importance, 1 being most important and 5 being least important for the care of residents at EOL: Comfort care Nourishment Symptom management Quality of life Care aligns with resident's beliefs/culture	Frequency rated as 1,2,3,4,5
Could you provide your reasons for choosing ___ as the most important one?	Content analysis - Where does food rank?
Are there any other aspects that are important to consider for residents at EOL and their caregivers?	Content analysis

Continued…

What role does food and eating play at EOL in LTC?	Content analysis
2. What do EOL nutrition conversations in LTC currently look like? **3. What EOL nutrition information is beneficial for caregivers to support decision-making?**	
Question	**Analysis**
Tell me about EOL conversations you have already had with caregivers a. What topics were covered? Prompt: food and nutrition→expand if mentioned, ask if not mentioned b. In your opinion, which topics are the most important to cover?	Content analysis
Tell me what nutrition in a death looks like, either what you believe it should be or if you've seen a good death in a resident, what the nutrition care looked like	Content analysis
4. What are the most effective delivery methods for EOL nutrition information once the resident is admitted into an LTC setting?	
Question	**Analysis**
How is EOL nutrition information currently presented to residents and their caregivers?	Content analysis
Are there any other ways EOL information could be presented to residents and their caregivers?	Content analysis
5. When should EOL nutrition information be discussed with caregivers?	
Question	**Analysis**
Under what circumstances should EOL conversations about nutrition and changes in	Content analysis

Continued…

the ability of a resident to eat or drink be initiated? a. Prompt: (i.e. sudden change in health status, general decline, nutrition changes such as dysphagia or weight loss)?	
When should EOL conversations about nutrition and about the possibility of changes in resident's ability to eat or drink, be initiated? Rank in order of importance, 1 being most important and 5 being least important: On admission In a care conference When resident is actively dying Development of feeding and swallowing issues Changes in intake Could you provide your reasons for choosing ___ as the most important one?	Frequency rated as 1,2,3,4,5 Content analysis Content analysis
How frequent should EOL nutrition conversations occur?	Content analysis
6. What is the current process for delivering EOL nutrition conversations?	
Question	**Analysis**
Are there formal policies or practices in LTC for EOL that you follow? Yes/No	Frequency Content analysis
Are you part of a team that initiates EOL conversations with residents and caregivers? a. Yes/No	Frequency Content analysis

Continued…

i. If Yes, who is on this team? (position titles, not names) ii. If No, who initiates the conversations in your LTC home? (position title, not names)	
How frequent is the discussion of nutrition in EOL conversations?	Content analysis
When are EOL nutrition conversations in LTC currently initiated? 1 (too early) 2 3 4 5 (too late) N/A (not discussed) Why do you feel this way?	Mean, standard deviation Content analysis
How comfortable are you with initiating and continuing EOL conversations with caregivers and residents in LTC? 1 (very comfortable) 2 3 4 5 (uncomfortable) Why do you feel this way?	Mean, standard deviations Content analysis
What would allow you to feel more confident participating in EOL conversations? a. Are there any specific resources or training to help you do so?	Content analysis
7. What impact has COVID-19 had on EOL conversations in LTC homes?	
Question	**Analysis**
What changes have you had to make with COVID-19 in relation to EOL conversations?	Content analysis

Continued…

What changes have you had to make with COVID-19 in relation to the timing of and information provided in EOL nutrition conversations?	Content analysis

Audio recordings of the interviews were transcribed verbatim and rechecked by the researcher (HP) and research assistant (MH), and all qualitative data (interviews) were organized using Microsoft Word (Version 16.62, 2022). Inductive content analysis is a method of qualitative analysis that can be used for research topics not previously studied; therefore it was chosen for this study due to the research gaps discussed in Chapter 2. It is also used frequently in gerontological nursing studies, which is related to this study. Content analysis involves three phases: preparation, organization, and reporting (Elo & Kyngäs, 2008). Preparation involved familiarization with the data by reading and re-reading through the interviews while taking notes on the general ideas discussed in the text (Burnard, 1991; Erlingsson & Brysiewicz, 2017). In this study, the manifest (literal) content was examined. The next phase is organization, which involved open coding, grouping, and creation of subcategories and categories. Codes were freely created from the text, then grouped into categories (Burnard, 1991; Elo & Kyngäs, 2008). From the categories, sub-themes and the overall theme were created, which represents higher levels of abstraction (Erlingsson & Brysiewicz, 2017). During data analysis, the researcher had to determine which sentences and/or phrases are relevant to the research question, and this is then classified as an open code (Kyngäs, 2020).

In this study, multiple steps were taken to ensure trustworthiness of the findings. Credibility of the qualitative data, more specifically truthfulness, was ensured by indicating to participants at the beginning of the interview there is no right or wrong responses, informing them they are allowed to withdraw at any time, and emphasizing that responses are confidential and not shared with the facility they work at. Frequent debriefing between researcher team members also occurred to ensure that any researcher biases were recognized (Shenton, 2004). As previously mentioned, the iterative process of concurrent data collection and analysis allowed the researcher to see what was known already, and what needs to be known (Morse et al., 2002). To ensure rigor and accuracy of the analysis, the following was done (Shenton, 2004): transcription

checking and verification with a second researcher (MH), vigilant review/reading of the transcripts to develop initial codes, coding verification for agreement, constant comparison of new and existing data for agreement, relevancy, and comprehensiveness, and the application of final codes to all the text with attention to maintaining the trustworthiness of the findings. It is also important to note that reality can be interpreted in different ways depending on each participant's subjective experience, therefore there is always a degree of interpretation when reading through and analyzing interview text (Graneheim & Lundman, 2004). Authenticity was ensured through the inclusion of participant quotes to show connection between the results and the data (Kyngäs et al., 2020).

In terms of process, the researcher (HP) conducted all the interviews and transcribed some (n=10), as well as coded the transcripts. The research assistant (MH) also transcribed some interviews (n=6) and coded them. To ensure consistency in the language used for coding, a coding table was created with new codes being added as needed (Appendix H). The codes were then organized by category and sub-theme and this was given to the research assistant, who coded the transcripts by category. The team met to go over each category to check for agreement with re-coding done as necessary. Disagreement between each person's codes was addressed by having each explain why they chose a specific category, then discussing which one best represents the data. Relevant participant quotes were also pulled to further illustrate each category.

Memoing was used to record the perspectives of the researcher through the data analysis process. They are snapshots of the thought processes of the researcher and backs up decisions made (Birks et al., 2008). Operational memos document the steps taken in data collection and analysis, and coding memos document the process of coding and categorizing the data. These memos are beneficial in research team meetings to explain to other why a certain decision was made. Preliminary thoughts on categories were written, helping to form the final themes.

The Theory of Holistic Comfort (THC) was used to guide this research study, specifically the development of two questions and the analysis of the open-ended responses. Open-ended questions #1 and #2 (Appendix B) were shaped by THC as it allowed the participant to discuss aspects of EOL care that are important and provide the most comfort to residents, and the role of food in providing comfort. During the data analysis of all the open-ended responses, instances of the four comfort dimensions were noted as they came up in the transcripts.

A timeline showing when recruitment, data collection, and analysis was done is presented in Appendix D.

Ethics

Ethics approval for this study was received from the Research Ethics Board (REB 2) at the University of Manitoba (Protocol # J2020:036). (Appendix E). Additional approval was received from the Prairie Mountain Health and Southern Health-Santé Sud (Appendix F; Appendix G).

Risks

Due to the recent impact of the COVID-19 pandemic on LTC as a whole (residents, staff, volunteers, family/friends), the interviewer (HP) took great care to be emotionally present and actively listen. Telephone numbers for resources at Health Links, Canadian Mental Health Association Winnipeg Phone Line, and the WRHA Mobile Crisis Service were included in the consent form. Risk in this research was no greater than in everyday life.

CHAPTER 4: NAVIGATING THE NUTRITION INFORMATION LANDSCAPE FOR HEALTHCARE PROVIDERS OF RESIDENTS IN LONG-TERM CARE HOMES AT THE END OF LIFE

Introduction

In Canada, the proportion of individuals over the age of 65 years is approximately 19% (Statistics Canada, 2022) and this number is projected to increase over the coming years. Seven percent of Canadian older adults currently live in a collective dwelling that provides medical care, such as a nursing home or long-term care (LTC) home (Statistics Canada, 2016). Most residents die in LTC (78.3%) with the remaining 21.7% being transferred into a hospital, another residential care home, or into a home at end of life (EOL) (Canadian Institute for Health Information, 2020b), highlighting the importance of EOL care being provided in the facility. The average length of stay in LTC is approximately 1.5 years (Hoben et al., 2019). Of residents living in LTC, 6.4% are under the age of 65 (Canadian Institute for Health Information, 2020b). Younger adults with intellectual or developmental disabilities may be admitted into LTC as their care needs cannot be met in the community (Canadian Healthcare Association, 2009; Ouellette-Kuntz et al., 2017). This study focuses on older adults, or those over the age of 65.

EOL care is typically defined as the care provided in the final months, weeks, or days of life, and is synonymous with terminal care (Hui et al., 2014). The dying trajectory of older adults is not predictable, making it difficult to define when a resident is at EOL and actively dying (Banerjee & Rewegan, 2016; Bern-Klug, 2009). Some residents die unexpectedly in their sleep while others may live with advanced disease for years (Bern-Klug, 2009). It can also be difficult to predict the dying phase of residents with frailty as it is characterized by a gradual decrease in function (Hall et al., 2021; Lynn, 2005). Based on the challenge of determining when a resident is nearing death, the term EOL will be used to describe the care provided to all residents from the time of admission until their death. In this context, not all residents are actively dying, but they are at EOL due to the expected decline in health while in LTC (Bern-Klug, 2009). This definition will only be used to discuss the care of residents 65 years of age and older.

Nutrition at EOL is important to address as the meaning of food changes when one develops a condition that affects taste, swallowing, and loss of pleasure in food (McQuestion et al., 2011). The goal of nutritional care at EOL is no longer maintaining optimal nutritional status, but rather meeting the holistic needs of the resident, their family/friends, and ensuring comfort

and quality of life (QOL) until the end of life. (Prevost & Grach, 2012). Management of disease moves towards more of a holistic approach promoting comfort, managing symptoms, avoiding hospitalizations, and preserving dignity and QOL (Dunning, 2020; Munshi et al., 2016; Pandya et al., 2020). This approach to nutrition aligns with the palliative approach in that it not only addresses the physical needs of the resident, but also the psychological and emotional needs of both the resident and their caregivers (Prevost & Grach, 2012; World Health Organization, 2020).

Canada currently does not have a national palliative policy guiding practices at EOL and of existing documents that guide palliative care, LTC was only discussed minimally (Fowler & Hammer, 2013; Hill et al., 2019). Specific nutrition guidelines for this stage are also lacking, which has been shown to be a major contributor to inconsistent practices in an inpatient hospital setting (Miles et al., 2016). Other countries such as New Zealand have an established palliative care strategy that includes provision of food, but it is discussed in the context of the final days of life (Ministry of Health, 2015). In Ireland, nutrition is only discussed as something that dietitians have an increasing role in (National Clinical Programme for Palliative Care, 2019). Across Canada, seven provinces and two territories have palliative care strategies or frameworks, however, Manitoba has no consistent provincial palliative care strategy and instead each regional health authority develops their own program (Canadian Institute for Health Information, 2018a). After examining the provincial and national palliative care frameworks, which outline what a future palliative care policy should look like, nutrition is not included.

As we are aware, there has been very little research done examining the perspectives surrounding EOL nutrition in LTC. Existing literature frequently does not include the perspectives of dietitians, despite the fact that nutrition is their expertise. The objectives of this study were to:

1. Examine the food and eating perspectives of healthcare providers (HCPs) of residents at the EOL in Manitoba LTC homes to determine the best information to guide EOL conversations with residents and caregivers.
2. Determine when nutrition EOL information would be the most beneficial, and what are the most effective delivery methods once the resident is admitted into a LTC setting.

Methods

Setting

In Manitoba, just over 17% of the population is over the age of 65 years (Statistics Canada, 2022). In 2020-2021, there were 7233 individuals in LTC homes (Canadian Institute for Health Information, 2020b). The province has 125 LTC homes within the five health regions (Canadian Institute for Health Information, 2021; Government of Manitoba, n.d.-c).

Study Population

HCPs working in LTC homes in Manitoba were recruited for this study, including nurses and other allied HCPs, including registered dietitians and healthcare aides. Convenience sampling was used, with recruitment material being sent out through regional health authorities throughout Manitoba and HCP networks via email. Participant inclusion criteria were: 1) held a position working as a healthcare provider in one or more LTC homes in Manitoba for at least the past two years (began working before March 2020) so that participants would be able to provide insight on EOL nutrition conversations in normal times and during the pandemic; 2) participate in EOL discussions at their LTC home; and 3) able to carry out conversations in English. Participants completed consent forms prior to participation in the study.

Interview Guide

The interview guide consisted of 23 questions: six demographic such as age, sex, occupation, and length of time working in LTC, two Likert scales to rate timing of and comfort with EOL nutrition conversations, two ranking questions where participants ranked five items in order of importance (one to five with one being most important and five being least important), and 13 open-ended questions assessing perceptions regarding nutrition and EOL conversations in LTC with residents and their caregivers. The questions for the interview guide were developed in consultation with my advisor and reviewing the literature on EOL. All questions were reviewed by the researchers and two experts in the field (a dietitian and an academic) for relevancy to the study objectives, flow and appropriateness, and comprehensibility for the research participants.

Data Collection Process

Semi-structured interviews were conducted over the phone due to the COVID-19 pandemic provincial restrictions. Each interview took 30-60 minutes, were audio-recorded,

transcribed verbatim, and participants were identified by a randomized numerical identifier to ensure anonymity. Sample size required to reach saturation cannot be predicted *a priori* (Sim et al., 2018), therefore interviews were continued until no new themes emerged in the transcripts, signalling that saturation was reached. Concurrent interviewing, transcription, and coding were completed, which was essential to ensuring reliability and validity as it allowed the researcher to see which topics were covered through the interviews (Morse et al., 2002).

Data Analysis

Descriptive data analysis was conducted for participant characteristics, rankings, and Likert questions (means, standard deviations, frequency). Open-ended questions from the transcripts were analyzed using inductive content analysis, a type of qualitative analysis. Content analysis allows for examining a phenomenon that had not been previously studied (Elo & Kyngäs, 2008), therefore it was chosen due to the lack of research on EOL nutritional conversations. Credibility of the qualitative data, more specifically truthfulness, was ensured by informing participants: there are no right or wrong responses, they can withdraw from the study at any time, and all responses are confidential. To ensure rigor and accuracy of qualitative analysis, the following was done (Shenton, 2004): transcription checking and verification with a research assistant, vigilant review/reading of the transcripts to develop initial codes, coding verification for agreement, constant comparison of new and existing data for agreement, relevancy, and comprehensiveness, and the application of final codes to all the text with attention to maintaining the trustworthiness of the findings. The researcher (HP) conducted all the interviews and transcribed some (n=10), as well as coded the transcripts. The research assistant (MH) also transcribed some interviews (n=6) and coded them. These two team members reviewed codes together to check for agreement with re-coding done as necessary. A coding table was created to ensure consistency in the language used for coding, with new codes being added as they emerged (Appendix H). Disagreement between codes was addressed by having each explain why they chose a specific code/category, then discussing which one best represents the data.

Ethics

Ethics approval for this study was received from the University of Manitoba Research Ethics Board (REB 2) (Protocol # J2020:036). Additional approvals were received from the Prairie Mountain Health and Southern Health-Santé Sud regions.

Results

Participant Characteristics

A total of 16 HCP participated in the study. A summary of study participants' characteristics can be found in Table 4.1. Most of the participants were female (87.5%) and from the Winnipeg Regional Health Authority (75%). Length of time working in LTC ranged from two to 35 years, with the mean being 12.4 ± 8.5 years. Most of the study participants were dietitians (62.5%).

Only 18.3% of the participants stated that they followed formal practices for EOL. One uses an algorithm and the other uses a checklist of what needs to be done from the moment someone is deemed to be at EOL to after death. Seventy-five percent are part of a team that initiates EOL conversations with caregivers. Participants found that EOL conversations were initiated at an appropriate time (3.6 ± 0.71) on a scale of one (too early) to five (too late). It was also found that participants were very comfortable with initiating and continuing EOL conversations with caregiver (1.56 ± 0.73) on a scale of one (very comfortable) to five (uncomfortable). Reasoning for both ratings were provided and are discussed with the results of the qualitative analysis below.

Table 4.1 Demographic characteristics

Characteristics	% (n)
Total number of participants	16
Age (years)	
Mean + SD	42.2 ± 10.2
Sex	
Female	87.5 (14)
Male	12.5 (2)
Time working in LTC (years)	
Mean + SD	12.4 ± 8.5
Equivalent full time (EFT)	
Mean + SD	0.8 ± 0.28
EFT Breakdown	
1.0	62.2 (5 nurses, 1 healthcare aide, 4 dietitians)[a]
0.9	6.3 (1 dietitian)
0.8	6.3 (1 dietitian)
0.6	6.3 (1 dietitian)[b]
0.5	6.3 (1 dietitian)
0.4	6.3 (1 dietitian)
0.1	6.3 (1 dietitian)
Region	
Winnipeg Regional Health Authority	75.0 (12)
Southern Health	6.3 (1)
Prairie Mountain Health	12.4 (2)
Interlake-Eastern	6.3 (1)
Occupation	
Dietitian	62.5 (10)
Nurse	31.2 (5)
Health Care Aide	6.3 (1)

[a] Three dietitians held two positions: 0.8 and 0.2 (n=2), 0.7 and 0.3 (n=1)

[b] Held two positions: 0.2 and 0.4

Participants were asked to rank the following five items in order of importance for the care of residents at EOL: comfort care, nourishment, symptom management, quality of life, and care that aligns with the resident's beliefs/culture. Comfort care was ranked as the most important and nourishment the least. They were then asked to rank the following five items in order of importance for when EOL nutrition conversations should be initiated: on admission, in a care conference, when the resident is actively dying, development of feeding and swallowing issues, and changes in intake. On admission was ranked as the most important seven times, and least important six times, highlighting the lack of consensus. Figures 4.1 and 4.2 shows the results for these questions.

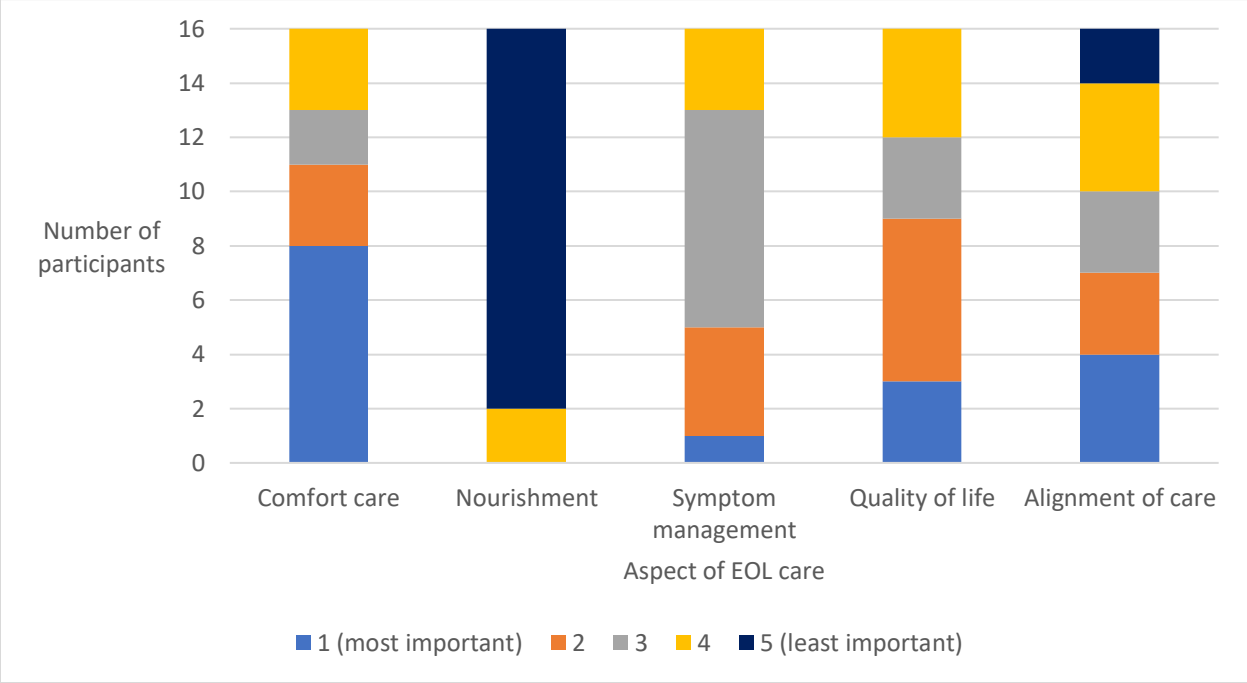

Figure 4.1 Participant ranking of the importance of aspects of EOL care

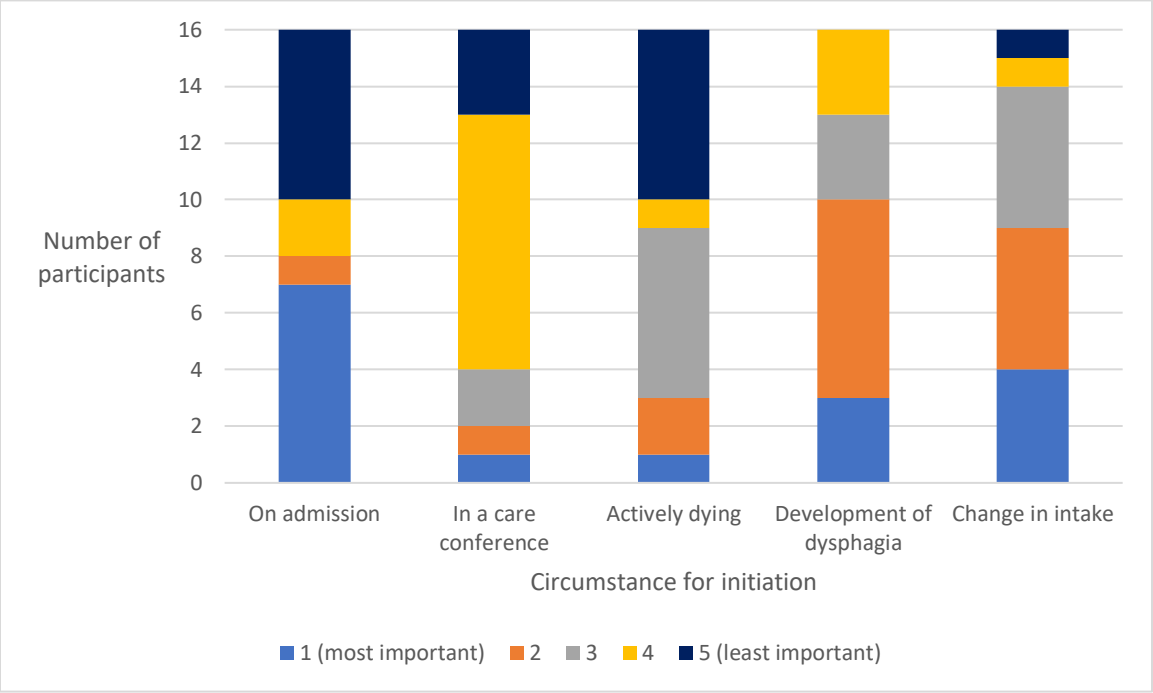

Figure 4.2 Participant ranking of the importance of circumstances initiating EOL conversations

Study Theme, Sub-themes, and Categories

The overall theme that was found from the qualitative interviews was negotiating tensions in nutrition at EOL which is supported by two sub-themes, balancing comfort and nutritional needs, and bridging the nutritional divide. Table 4.2 displays categories with their respective definitions and additional quotes for each sub-theme.

Main Study Theme: Negotiating tensions in nutrition at EOL

This overall theme highlights how at EOL, tensions arise from differing expectations of care and the importance of nutrition of the HCPs, caregivers, and sometimes residents. HCPs respond to these challenges by providing education on EOL nutrition in order to bridge the divide between what caregivers believe and what is best for the comfort of the resident.

Sub-theme 1: Balancing comfort and nutritional needs

This sub-theme involves managing the expectations and knowledge of caregiver, residents, and HCPs themselves. The meaning of food for caregivers and HCPs is included, and how HCPs support caregivers during the EOL process.

Considering both resident and caregivers wishes at EOL

Caregivers have differing levels of understanding on EOL, and this could impact the quality of death for the resident. Many HCPs stated that a common issue they faced was that caregivers are still wanting to feed the resident at EOL and believe that eating will allow them to live longer: "There's so many people who are like, you know, 'if mom will just eat one bite, if mom wanted it then she won't die,' and people really believe that, it's really shocking…" (P517)

When asked what a good death and QOL involves, ensuring resident needs are met was highlighted. EOL care needs to be individualized to meet the unique needs and wishes of the resident and comfort care is preferred over medical treatment. This may also involve taking risks and allowing the resident to eat food that is not appropriate for them physically but brings them comfort and other positive feelings. Some HCPs also discussed that they prefer not to bring up conversations about EOL care in front of residents: "…you don't always love having those conversations in front of the patients themselves whether they're awake or not, I believe that they can still hear you…" (P802)

Food has many meanings at EOL

Food plays many roles, from physical, to emotional, to no role at all. Maintaining nutritional status is not as important at EOL. Most HCPs stated that food plays a less active role and is used for comfort by providing food that the resident wants: "…at the end of life I don't feel that food is actually, it's not necessary, it's not really providing, when someone is at the end of life food is not nourishment anymore" (717). For a small number of HCPs, they see food as still having a role in prolonging the life of residents: "…like the longer they can eat and nourish themselves the longer they'll be with us, but ya, as soon as they stop eating it's, that's kind of, you know, the end stage." (P905)

Role of healthcare providers

To balance comfort and nutritional needs, HCPs provide education to caregivers on various EOL topics, as well as provide support to them. They also collaborate with other HCPs to ensure excellent care for the resident. Participants say that one of the most important pieces of education they provide to caregivers is on the dying process and how food is not necessary at EOL. The focus of care becomes on the goal of comfort and how caregivers can show their love through ways other than food. HCPs also comfort the family through building rapport, providing frequent updates on resident status, and being compassionate towards their needs.

A barrier to HCPs, especially dietitians to having these conversations and more contact with caregivers, is their equivalent full time (EFT is used in Manitoba and is the same as full time equivalent- FTE). Four of the dietitians interviewed hold two positions either in different homes or within the same home, decreasing their availability to make connections and converse with caregivers. Others held low EFT positions, also decreasing their ability to connect with caregivers. This was articulated by one of the participants:

> If you have a really terrible EFT or position, and you might not be able to have those [EOL] conversations, you might not even be asked to be involved in those conversations as a dietitian. And other disciplines might not even think to bring you into those conversations unfortunately because the EFT historically has been really terrible, at least in Manitoba. (P971)

Sub-theme 2: Bridging the nutritional divide

This sub-theme involves the processes for the delivery of EOL nutrition information, including how it is delivered, and timing for initiation and continuation of the conversation. The comfort of HCPs in having these conversations is also addressed within this sub-theme.

Delivery of EOL nutrition information

To bridge the nutritional divide, EOL nutrition information is provided to caregivers through various ways, including in-person conversations with an interdisciplinary team. In-person conversations were regarded as the best method, as they allow the HCP to read the body language of the caregiver to assess how the information is being received. Resources, often

provided by the health region or company, are used to supplement the conversations and allow caregivers to take their time to read through them.

Who initiates EOL conversations varies with each home. Typically a nurse is involved, however, the team may involve other members depending on the needs of the resident as well as caregiver. Dietitians are not always involved, but depending on the situation as well as their availability, may participate.

> So at my homes it's [having EOL conversations] usually only if the nurse involves me [RD] and needs me to discuss things with the family. Usually I'll touch base with the family and let them know that I'm here and I'm here to support them with the team and if they need anything to let the nurse know and I can do some follow-ups but for the most part, it's usually through the nurses just because I'm not at each home full time." (P178)

When to initiate and continue conversations

EOL nutrition conversations are typically initiated when there is a change in condition or on admission. When it is brought up on or shortly after admission, these conversations are not as in-depth and just involve making the caregivers aware of some expected changes that may occur in the resident. Some HCPs believe that it is too overwhelming to discuss at admission and it is inappropriate to bring up EOL too early. Change in condition, such a weight loss, decreased intake, development of dysphagia, or other irreversible changes is seen as an appropriate time to discuss expected changes in the ability of a resident to eat and drink. Overall, there was no consensus on when the best time to initiate EOL nutrition conversations, with opinions ranging from on admission to when the resident is actively dying: "Ya, like I hate to say that we wait until they're palliative to worry about their nutrition but, I mean we definitely do before then but once they're palliative we have that discussion with the family" (P905)

The continuation of EOL conversations is dependent on the condition of the resident and understanding of the caregivers. If caregivers are well-receptive to the information when it is first presented to them, there may not be a need to bring it up again. For others, a further change in the resident's condition may warrant another conversation to reiterate the information and answer any questions they may have.

> … it [EOL conversations] can be as frequent as monthly, or it can honestly be sometimes a one-time conversation. Some families just get it, or they work in healthcare, or they've had another loved one that's gone through the same thing. So, if it's quite clear that they are on the same page and they understand end of life nutrition then it's often maybe just a one-time conversation…. So again, case dependent, resident dependent, family dependent, on how frequent to have that conversation. (P483)

Contributors of HCP comfort and resources to develop confidence

Experience is the biggest contributor to HCP comfort with EOL nutrition conversations. HCPs said that the more deaths they experience, the more comfortable they are with the topic, that it is "a reality of the work" (P640).

Education and opportunities for experience need to be integrated into education and practicum programs. Many HCPs said that they didn't get practical training in their internship/practicum: "…I know when I went through my internship, I really didn't get any exposure to this [EOL], really." (P178). Some sought education on their own through attending conferences and workshops put on by other disciplines. It was recommended that newer HCPs find opportunities to sit-in on EOL conversations and receive mentoring from more senior staff.

> Like it's all well and good to say that we need to have them [education], but someone like myself, I needed the right words so I had conversations and said 'hey you're gonna have a conversation with someone, can I listen with you? I don't need to participate I just want to hear what you say and how you say it and how do you deal with difficult people, and so having those opportunities was really important, I didn't have to be part of the conversation, I just wanted to sit in and observe the conversation.' (P971)

EOL policies and practices

Another means of bridging the nutritional divide is through policies. LTC homes vary in what informal and formal policies and practices guide EOL care. As previously mentioned, only three HCPs stated that they have formal policies and practices for EOL that they follow. Another common thing heard in the interviews was that while nursing may have policies/practices, there were none for nutrition: "And I don't know if we do have like an end of life nutrition care policy.

… nothing really specific to palliative care and nutrition conversations or anything like that." (P348)

For those that did have policies or practices they followed, they were commonly specific to the company or health region. They were also used more often during the final few days when the resident is actively dying.

Table 4.2 Study sub-themes and select participant quotes

Categories	**Definition**	**Participant quotes**
Sub-theme 1: Balancing comfort and nutritional needs		
Considering both resident and caregiver wishes at EOL	Caregivers have differing levels of understanding on EOL, and this could impact the quality of death for the resident.	"…number 1 [goal] is to find out where the family is at. What are the issues that they see and what is their understanding?" (P221) "They [caregivers] feel the choices have been taken away from them and that's one thing to keep control and have a choice, whether they want supplement or not, so those are hard discussions to talk to them and say, 'you know, this person is living, but they're living because you want them too, not because their body is really able to.'" (P178)
Role of healthcare provider	HCPs provide education to caregivers on various EOL topics, as well as provide support to them. They also collaborate with other HCPs to ensure excellent care for the resident.	"I think the other issue is talking about how as people approach end of life, their body systems, to put things in layman language, are reduced, such that people are not able to utilize the food nutrition that they are receiving and there also is potential that negative consequences associated with it, such as bloating, diarrhea, such as fluid congestion for example." (P221) "So, at the personal care home that I currently work at we try to give information on admission on safe feeding and swallowing, what can happen if someone has dementia and the progression of nutrition symptoms and how that could play out in someone's future…" (P348)
Food has many meanings at EOL	Food plays many roles, from physical, to emotional, to no role at all. Maintaining nutritional status is not as important.	"…it's not nutrition at that, yeah, it's not nutrition at that point, right? Like it's just food and fluids like just for comfort sake, right? Because they can't do anything with it and really it's not gonna sustain them" (P517) "Ya, so it's [food] important because as we all know that's kinda the foundation of our body, so you need proper nutrition, proper

Continued…

Categories	Definition	Participant quotes
		nourishment in order for you to have a good quality of life. So I think that part of the thing is that you use nutrition in order to promote the person's quality of life." (P121)
Sub-theme 2: Bridging the nutritional divide		
Delivery of EOL nutrition information	EOL nutrition information is provided to caregivers through various ways, including in-person conversations with an interdisciplinary team.	"…we have an end of life committee but no formalized team, so again, it's, what tends to happen is myself, the unit coordinator for the unit or the full time nurse will often initiate the conversation together. As I've been by myself [dietitian], depending again on the situation, the team so to speak, or the quote unquote team that exists is typically myself and a nurse" (P315) "A nurse, a manager, I don't think a health care aide would [initiate], I don't think any of the other allied health would, I suppose speech language pathology might talk about like deteriorating swallow and someone's inability to safely consume any foods anymore but they wouldn't really be talking about nutrition per say. Well I guess spiritual health, social work, nurse, manager, dietitian; I think that would probably be the team to talk about it but I think dietitian would take the lead on the nutrition part" (P401)
EOL policies and practices	LTC homes vary in what informal/formal policies and practices guide EOL care	"Ya not any written policies that I'm aware of in terms of, you know, when to stop providing food. No, not that I'm aware of. We talk about it but I don't think there's any policies." (P401) "Specific to our homes, I don't think there's any specific procedures in place… There's not a lot of discussion I find, like open discussion about end of life nutrition… there probably are some sort of processes in place for that, I don't know what they are and I just sort of do my own thing as I see fit because I think I'm probably one of the people that maybe feels a little bit more comfortable having that conversation…." (P483)

Continued…

Categories	Definition	Participant quotes
When to initiate and continue conversations	EOL nutrition conversations are typically initiated when there is a change in condition or on admission. The continuation of EOL conversations is dependent on the condition of the resident and understanding of the caregivers.	"When it's more of a, when you can sort of see the transition towards end of life, I do try to have that conversation earlier rather than later…" (P483) "I think I've just had, just some where it has been too late and it's kind of been branded in my memory of the mistake that it was introduced too late. Not all of the conversations are introduced too late, but when they are, you remember them… (P348) …on admission or maybe a few weeks after at a post-admission conference we talk with him [resident] or once he's settled I talk with him or we provide him, provide them with some resources or we provide families with resources and then probably it's not brought up again unless family's calling again about it or unless he in fact is at end of life. (P717)
Contributors to HCP comfort and resources to develop confidence	Experience is the biggest contributor to HCP comfort with EOL nutrition conversations. Education and opportunities for experience need to be integrated into education and practicum programs.	"As I've worked here longer and become older myself, I've been able to, you know, grow wiser so you can, and then again with behaviour training, behaviour modification training and things like that that we've had, you begin to understand people a little bit more." (P717) "There was no training, you just get it as you go through more deaths. That's just how it happened for me…" (P505)

Discussion

This qualitative study examined the food and eating perspectives of HCPs in LTC to determine what information would be the most beneficial and what are the most effective delivery strategies for EOL. HCPs have to navigate tensions that arise at EOL by balancing comfort and nutritional needs of the resident and the processes for EOL nutrition conversations with caregivers. HCPs and caregivers often have different beliefs regarding the role of food at EOL, therefore HCPs provide education to caregivers on this topic. When looking at timing of initiation of EOL nutrition conversations, there is no consensus on the best time, but earlier is best to properly prepare caregivers for the EOL process.

At the beginning of each interview, the definition of EOL was provided to participants as "the care provided to all residents from the time of admission until their death." Throughout the interviews, when HCPs were discussing EOL they used it in the context of the final weeks or days of life when death is more imminent. In the literature on EOL care in LTC, many HCPs defined EOL as the period of time when death is imminent, the final stage of life (Froggatt & Payne, 2006; Wallace et al., 2017). In recent years a palliative approach in LTC has been emphasized that includes care from time of admission to death (Cloutier et al., 2021; Froggatt et al., 2020; Kaasalainen et al., 2019, 2020). This approach to care is appropriate for older adults with a neurogenerative disease and other illnesses other than cancer, which palliative care has traditionally focused on (Kristjanson et al., 2003).

HCPs brought up in the interviews that caregivers struggled accepting decreased food intake among residents at EOL. Food not only plays a physical role, but also has social and symbolic meanings. Feeding is a way that caregivers show they care. The idea that caregivers have that food and eating will allow a dying person to live longer is one that is commonly seen in the literature in a number of countries (Hilário & Augusto, 2021; McInerney, 1992; Raijmakers et al., 2013). For most HCPs in the study, maintaining nutritional status was no longer a priority. Comfort is more important than proper nutrition and prolonging life (Schütte et al., 2020). Artificial nutrition and hydration are also to be avoided (van der Steen et al., 2014). Many HCPs highlighted that when a person is dying, trying to feed them can cause more discomfort or harm to the resident. Part of the education provided to caregivers is that at EOL, individuals who are not eating or drinking are not uncomfortable and proper mouthcare can alleviate any discomfort (van der Riet et al., 2008).

The best opportunities for EOL nutrition conversations were on admission, or when the resident develops dysphagia or any other irreversible change in condition. These events have been identified in other studies as ones more likely to lead to EOL conversations with caregivers. Again, it was identified that there is no one ideal time to educate caregivers about the EOL process (Daneau et al., 2022). When one is diagnosed with a life-limiting illness, early discussions regarding EOL care can feel confrontational but also allows the individual and their caregivers a chance to have open conversation about the topic and greater acceptability of EOL practices (Fliedner et al., 2019). These initial conversations commonly involve education about disease progression, particularly dementia progression as it affects 63.2% of residents in LTC (Canadian Institute for Health Information, 2020b). Providing disease-specific information to caregivers helps them to become prepared for what is expected to occur, allows for reflection, and encourages conversations about care (Sussman, Kaasalainen, Bui, et al., 2017).

A barrier to EOL nutrition conversations is the EFT of HCPs. Of the 10 dietitians interviewed, only one held a full-time position in a single role. All other dietitians held less than 1.0 EFT in a single home, or two EFTs in different roles or homes. Some HCPs interviewed said that a low EFT does not allow them time to participate in EOL conversations. In a study of LTC dietitians in British Columbia, many say that the current hours they work are not enough to complete all the required tasks (Black et al., 2013). Reasons for time constraints include high resident turnover, more admissions of frail older adults, and increased number of referrals for nutrition consultation. Dietitians report that little time is left to contact caregivers to provide nutrition updates (Dietitians of Canada, 2016).

Throughout the study interviews, HCPs discussed the lack of educational and practicum opportunities in EOL care. In terms of dietitians specifically, many stated that they didn't receive EOL experience and education through their dietetic internship/practicum. Dietitians working in LTC may feel unprepared to deal with EOL, as a lack of exposure to this setting has been identified as an issue in new graduates entering practice (Brissette et al., 2014). This issue also extends to nurses and physicians as many feel that that additional training and education is needed to improve EOL care (Fien et al., 2021; Goddard et al., 2013). Formal education in palliative care and knowledge of the definition of palliative care are associated with higher self-efficacy in EOL conversations (Evenblij et al., 2019).

Future research should examine EOL nutrition conversation practices Canada-wide for the development of a national palliative care policy. It should also include residents and their caregivers to examine their perspectives regarding EOL nutrition as palliative care addresses the needs of both (World Health Organization, 2020). The EOL perspectives of each HCP discipline should be analyzed separately to see if there are any differences in knowledge and beliefs on EOL nutrition, which can help tailor educational materials. The role of cultural and/or religious affiliation of the home should also be examined to assess if it affects EOL nutritional conversations and practices.

Study Strengths

A strength of this study is the inclusion of dietitians as the majority of current research on EOL care only includes those providing direct care to the resident, such as nurses and physicians (Cagle et al., 2017; Firnhaber et al., 2020; Handley et al., 2022) There is a desire from dietitians to be more involved in palliative care (Pinto et al., 2016).

Limitations

This study has a few limitations. Convenience sampling was used for participant recruitment and the data may not represent all HCP perspectives from all health disciplines in Manitoba LTC homes. As discussed in the interview, there are other HCPs such as social workers, spiritual health workers, and physicians that take part in EOL conversations, but we were unable to recruit any. In addition, there were no participants from the northern region of Manitoba, therefore the finding may not be completely representative of provincial EOL nutrition practices. This data was collected over a 9-month timeframe where COVID-19 infections greatly impacted LTC and caused many outbreaks, hence difficulties in recruitment and data collection. From November 2021-March 2022, we did not recruit or interview HCPs as there were major COVID-19 outbreaks in LTC, and the health regions and our research team did not want to further overwhelm staff.

Conclusion

Data from this study shows that HCPs in LTC navigate tensions at EOL through balancing comfort and nutritional needs of the resident. For the most part, HCPs view food as something that is no longer necessary at EOL and plays a more significant role in comfort. A

second way that HCPs navigate tensions is through bridging the nutritional divide through education of caregivers. Education on disease progression and the consequences of feeding are important topics to address. There was no consensus on when the best time is to initiate EOL nutrition conversations, with opinions ranging from on admission to when the resident is actively dying. Further research is needed to examine EOL nutrition conversation in a wider context throughout Canada, as well as include the perspectives of residents and their caregivers.

CHAPTER 5: THE IMPACT OF COVID-19 ON END OF LIFE NUTRITION CONVERSATIONS AND PROCESSES IN LONG-TERM CARE: CHALLENGES AND STRATEGIES OF HEALTHCARE PROVIDERS

Introduction

End of life (EOL) care is provided to residents in long-term care (LTC) homes in their final one to two years of life (European Association for Palliative Care, 2009), and aims to support quality of life until their death. Too often, EOL care does not meet the expectations of caregivers as they often receive inconsistent and inadequate information about the resident's care and goals of care at EOL (Bern-Klug, 2009; Thompson et al., 2012). Caregivers are often unsure about what EOL care involves and have concerns about the staff's ability to care for their family member in LTC (Parker et al., 2016). HCPs often lack education on EOL care, which can negatively impact the care of residents (Cagle et al., 2017). Resident wishes for their death are not brought up in a timely manner, decreasing satisfaction of both the resident and their caregivers (Fowler & Hammer, 2013; Sussman, Kaasalainen, Mintzberg, et al., 2017). Issues regarding EOL care have been further amplified by COVID-19 (Rosa & Davidson, 2020) and brought to the public's attention by the pandemic and media reports of deaths in LTC homes.

In Canada, the COVID-19 pandemic devastated LTC homes between March to May 2020, where 80% of deaths from the virus came from within LTC (Canadian Institute for Health Information, 2020a). Issues surrounding nutrition during the first wave of the pandemic included residents receiving inadequate food and fluid due to the unavailability of staff to assist them with meals because of staff shortages and isolation, leading to weight loss, malnutrition, and death (Scaman et al., 2020). In regards to communication with caregivers, many family members did not receive the level of specificity they would have wanted about the status of the resident, and many were concerned that their loved one was not being cared for adequately (Stevenson, 2021). EOL care was impacted by the pandemic, but it was already lacking in LTC before the pandemic began (Canadian Institute for Health Information, n.d.). Guiding documents on COVID-19 in LTC focused more on infection prevention and control, and included very little on EOL care, failing to discuss communication with caregivers and education of staff (Gilissen et al., 2020).

As we are aware, there has been no research on the impact of COVID-19 on EOL nutrition practices in Canadian LTC homes. The objective of this study was to examine end of life nutrition conversations and processes of healthcare providers (HCP) in LTC homes during

COVID-19. This involves the timing and content of EOL conversations, as well as daily practices of HCPs that relate to EOL care of residents.

Methods

Data Source

The data from this study was based on our exploratory qualitative study examining EOL conversations and processes of HCPs in LTC homes. We interviewed 16 HCPs from Manitoba LTC homes between July 2021 and April 2022. Using a semi-structured interview guide, 13 questions were asked during interviews to assess perceptions regarding nutrition and EOL conversations in LTC with residents and their caregivers. The final two questions addressed the impact of COVID-19 on communication with caregivers and changes to EOL conversations in general and specific to nutrition. The detailed methodology can be found in Chapter 4. For this manuscript, we will only present results pertaining to nutrition challenges and strategies of HCPs during COVID-19.

Study Population

Nurses and other allied HCP working in Manitoba LTC homes were recruited through regional health authorities and HCP networks via email and word of mouth. Participant inclusion criteria were: 1) held a position working in one or more LTC homes in Manitoba for at least the past two years starting in their position before the pandemic began (March 2020); 2) participate in EOL discussions at their LTC home; and 3) able to carry out conversations in English. Participants completed consent forms prior to participation in the study.

Data Collection

Telephone audio-recorded semi structured interviews were conducted with participants. Participants were asked what changes they had to make with COVID-19 in relation to EOL conversations in general and more specifically to nutrition. Demographic information such as age, sex, occupation, and length working in LTC was collected. The interviews were transcribed verbatim and participants were identified by a randomized numerical identifier to ensure anonymity. As sample size required to reach saturation cannot be predicted *a priori* (Sim et al.,

2018), interviews were continued until no new themes emerged in the transcripts, signalling that saturation was reached. The iterative process of concurrent data collection and analysis allowed the researcher to see what was already known, and what is still needed which is essential to ensuring reliability and validity (Morse et al., 2002).

Data Analysis

Descriptive statistics was conducted for participants' characteristics (means, standard deviations, frequency) using Microsoft Excel (Version 16.2, 2022).

Inductive content analysis is a type of qualitative analysis that was used in this study to analyze the interview transcripts. Content analysis allows for analyzing a phenomenon that has previously not been previously studied (Elo & Kyngäs, 2008), therefore it was chosen due to the lack of research on EOL nutritional conversations during COVID-19. To ensure rigor and accuracy of qualitative analysis, the following steps were carried out (Shenton, 2004): transcription checking and verification with a second researcher, vigilant review/reading of the transcripts to develop initial codes, coding verification for agreement, and constant comparison of new and existing data for agreement, relevancy, and comprehensiveness. The researcher (HP) conducted all the interviews and transcribed some (n =10), as well as coded the transcripts. The research assistant (MH) transcribed the remaining interviews (n=6) and coded them. These team members (HP and MH) checked for agreement with re-coding done as necessary. To ensure consistency in the language used for coding, a coding table was created and used. Disagreement between codes was addressed by having each explain why they chose a specific code/category, then discussing which one best represents the data.

Ethics approval for this study was received from the Research Ethics Board (REB 2) at the University of Manitoba (Protocol # J2020:036). Prairie Mountain Health, and Southern Health-Santé Sud.

Results

Sixteen participants were interviewed as data saturation was reached and no new themes emerged. The interviews ranged from 30 to 60 minutes. As noted in Table 1, most of the participants were female (87.5%), dietitians (62.5%), and worked in the Winnipeg Regional Health Authority (75%).

Table 5.1. Participant Characteristics

Characteristics	**% (n)**
Total number of participants	16
Age (years)	
Mean + SD	42.2 ± 10.2
Sex	
Female	87.5 (14)
Male	12.5 (2)
Time working in LTC (years)	
Mean + SD	12.4 ± 8.5
Equivalent full time (EFT)	
Mean + SD	0.8 ± 0.28
Region	
Winnipeg Regional Health Authority	75.0 (12)
Southern Health	6.3 (1)
Prairie Mountain Health	12.4 (2)
Interlake-Eastern	6.3 (1)
Occupation	
Dietitian	62.5 (10)
Nurse	31.2 (5)
Health Care Aide	6.3 (1)

Study Themes

Three themes emerged from the codes: 1) Modifications to EOL conversations and processes; 2) Adaptations of HCPs to new COVID-19 restrictions; and 3) Conversations about healthcare provided for residents with COVID-19. Components and additional participant quotes for each theme are shown in Table 2.

Theme 1: Modifications to EOL conversations and processes

EOL conversations and processes during COVID-19 required modification to accommodate new restrictions that impacted residents, caregivers, and HCPs. Most changes were related to visitor restrictions, including conversations over the phone, increased communication with caregivers, and delay in initiation of EOL conversations. Because of visitor restrictions, more information had to be relayed to caregivers, especially regarding the physical condition of the resident. Not being able to be in the LTC home made it harder for caregivers to understand or accept the resident's condition.

> Mostly families are requiring more information I would say because they are not here to actually see the patient's condition, so it's harder because as a nurse you kind of have to be more descriptive of the patient's condition, cuz the patient's family are not here to witness it as supposed to pre-COVID they would usually come visit and see what, why we're doing what we're doing. (P121)

For some HCPs, the only modification they had to make was that conversations with caregivers were over the phone and the content of EOL nutritional conversations remained the same, "I didn't provide any more or any less information that I usually do about end of life specifically or nutrition at end of life specifically." (P315)

Theme 2: Adaptations of HCPs to new COVID-19 restrictions

HCPs experienced changes in their daily practice as duties shifted and extra infection control methods were required. For many, dietitians had less of a role and often would hand off the role of having EOL nutrition conversations to nursing as nurses were in residents' rooms more.

> Like, I talk with the nurses and let them know things about end of life with nutrition… typically now the nurses are the frontline discussion for end of life, which for the dietitian is quite unfortunate because it is nice to have those conversations with the families, especially when you get to know them. (P802)

Since residents were required to stay in their rooms due to health restrictions, less physical cues such as weight were available for HCP assessments. Meetings as a palliative care team to discuss current practices were also stopped to reduce contact.

> As a team we used to do it [discuss EOL] once every 2 months, we would meet as a palliative care team and talk about this but with COVID we haven't been able to get together to do that and other things. We had COVID in our building so other things took precedence over that. (P505)

Theme 3: Conversations about healthcare provided for residents with COVID-19

Conversations about the care of residents with COVID-19 were much different than EOL conversations before the pandemic. EOL conversations were much more difficult due to the rapid and unpredictable progression of the virus.

> So those [EOL] conversations were very different from what they are when we're not talking about a COVID-positive person because COVID changed everything for the trajectory of the end of life journey cuz it was much faster, it was much more brutal… (P505).

With COVID came nutrition-related issues such as dysphagia, loss of appetite, and other changes in ability to tolerate diet.

> …[COVID] created a lot more conversations about end of life… And especially during the earlier waves when, when we had residents who were positive for COVID that had, you know, significantly more symptoms, more GI issues. You know, significantly decreased appetite. (P483)

Table 5.2: Study Themes and Supporting Quotes

Theme	Components	Participant quotes
Modifications to EOL conversations and processes	Over the phone or virtually Visitor restriction Discuss after 2-week post-admission quarantine Family less accepting of change Practices the same More communication with family Unable to develop relationship with family	"…families might not have been there [LTC home] to see that change [in condition] and might have a harder time accepting that that change was coming because they don't have the visual cues to see that Mom and Dad are eating less or they're starting to have physical changes and wasting, they might not have seen any of that so it was more difficult in some cases for them to identify with what you [HCP] were talking about." (P971) "…I guess there would have been a bit of a change with patients once [after admission], that conversation might happen once the person has been quarantined for 2 weeks on admission" (P717)
Adaptations of HCPs to new COVID-19 restrictions	Less physical cues (weight) Time constraints Unable to meet with palliative care team to discuss practices Less RD involvement RD hands off role to nurse	"I think the dietitians had to be even more mindful of having those [EOL] conversations and keeping up with it, and there was a lot of pressure to do so cuz it couldn't be taken on by another discipline, they were busy doing COVID related things…that all takes extra time so, you really have to be very mindful of doing weight reviews and that sort of thing" (P971) "And at that point that was primarily through nursing, that was less of an opportunity for me and that was certainly more shift of focus on nursing, having those conversations because they were in the COVID rooms" (P483).
Conversations about healthcare provided for residents with COVID-19	Difficult conversations Predicting health trajectory What to predict in COVID patients Severe cases warrant proactive approach Change in ability to tolerate diet New issues with COVID (blood sugar, swallowing)	"…it [COVID] changed everything, the whole conversation got tipped right upside down and thrown out the window and you had to make a whole new one on what are we doing, what do we hope to do, and how are we hoping to do this, and is it working or not? So those conversations were very different." (P505) "One of the signs we first notice of people having COVID is that they are unable to tolerate their current diet/fluid texture and/or tl

Continued…

	Respiratory distress	decreased appetite. This is then a huge change for families to understand and accept" (P517).

Discussion

This qualitative study examined end of life nutrition conversations and processes of HCPs in LTC homes during COVID-19. The three identified themes dealt with modifying EOL nutrition conversations and processes, adapting to new COVID-19 restrictions, and discussing the healthcare provided for residents with COVID-19. HCPs were still able to have EOL nutrition conversations, but they had to be over the phone as caregivers were unable to visit. The content of conversations with caregivers about residents infected with COVID were different due to the unique symptoms that came with infection. HCPs themselves were also impacted in their daily practices.

The findings of this study show that visitor restrictions impacted the initiation, frequency, and delivery of EOL conversations. Across interviews, the impact of visitor restrictions was a common issue brought up by HCPs. At the height of the pandemic, visitors were typically restricted to those with designated visitor status or when the resident was receiving EOL care. Visitation guidelines also varied provincially (Freeman, 2021). Caregivers of residents that died in LTC stated that they felt that the current restrictions partly or completely prevented their loved one from having their final wishes fulfilled (Mackenzie, 2022). Visitor restrictions also impacted how willing caregivers were to accept the fact that their loved one was dying, which was an issue that occurred before the pandemic (Harasym et al., 2020). In our study, the findings related to virtual conversations and visitor limitations are similar to studies done in other countries during COVID-19 (Gonella et al., 2022). Studies examining the perspective of bereaved caregivers during the pandemic highlight the impact of receiving updates over the phone and the lack of information they received (Hack et al., 2022; Pauli et al., 2022). Caregivers depend on HCPs to provide updates on the condition of the resident, but as shown in our study, HCP's change in roles made it difficult to gather indicators regarding residents' condition and have timely conversations with caregivers.

Adaptations that HCPs engaged in, such as stopping palliative care team meetings, can lead to feelings of loss in their daily structure. In a study on the impacts of COVID-19 in a Dutch nursing home, not having team meetings caused HCPs to have this sense of loss, but it also led to an increase in direct patient care. It is suggested that short informal evaluation moments, such as brief huddles, are more effective than large team meetings (Rutten et al., 2021). Other studies on nurses working through the pandemic also stated that activities not related to patient care or

infection control were stopped, thus allowing for an increase in direct care of patients (Melnikov et al., 2022).

The infection control measures put into place limited the ability of HCPs to do in-person assessments of resident status as it took extra time for donning and doffing of personal protective equipment. One way this was overcome in this study was by HCPs working with other disciplines to fill in the gaps. Other studies also highlighted the importance of collaboration in the care of residents (Vellani et al., 2021). Working as a team ensures that quality care remains to be provided during pandemics (Melnikov et al., 2022).

Infection with COVID-19 can be accompanied with gastrointestinal issues that affect nutrition, including nausea, vomiting, and diarrhea (Aguila et al., 2020), which was brought up by HCPs interviewed in this study. Little literature exists on managing these conditions in the LTC setting as research on nutrition and COVID-19 focuses on administration of artificial nutrition and hydration and/or in the acute care setting. As we are aware, no literature exists on management on gastrointestinal manifestations of COVID-19 in older adults in LTC at EOL.

This study has several strengths and limitations. Participants from several health disciplines were included, with the majority as dietitians as EOL studies frequently do not include their perspectives. In addition, all of the participants were involved in EOL conversations before and during the pandemic which provided a point of comparison not seen in other studies. Convenience sampling was used for participant recruitment and the data may not represent all HCP perspectives from all health disciplines in Manitoba LTC homes. There were also no participants from the northern region of Manitoba, therefore the finding may not be completely representative of the provincial COVID experience. In addition, this data was collected over a 9-month timeframe where COVID-19 infections in LTC changed dramatically, and research needed to be stopped and restarted which could have affected participant perspectives. Manitoba experienced four waves of outbreaks, and the perspectives gathered in this study vary as homes became more prepared in the later waves. Interviews began shortly after the height of the third wave and continued until after wave four.

Implications

The results from this study will help inform pandemic planning by providing insight on the unique challenges that arose from visitor restrictions and infection control procedures. The nutritional issues with COVID-19 such as decreased appetite and changes in ability to swallow

present the opportunity for dietitians to become more involved in EOL conversations. Policy planning should occur so that all residents receive quality EOL care even during a pandemic. This is another area that presents the opportunity to become involved as nutrition is their area of expertise.

Future Research

A recommendation for future research is to conduct a larger-scale study on EOL nutritional conversations and processes nation-wide to gather perspectives on the unique challenges across Canada as provinces and territories experienced differing sizes of outbreaks indicated by Detsky & Bogoch (2020). There is a research gap with nutrition in COVID-19 positive patients in LTC as the majority of the research carried out focuses on acute care settings (Mechanick et al., 2021). Finally, an additional opportunity for research is to evaluate the efficiency of palliative care team meetings in a post-COVID world in LTC as short informal meetings have been found to be effective and time-efficient, which has been shown to increase time available for direct patient care (Rutten et al., 2021).

Conclusion

COVID-19 greatly impacted the LTC sector and the practices of HCPs working in these facilities. Data from this study shows that HCPs in LTC had to make modifications to EOL nutrition conversations as well as adapt their own practices and processes due to visitor restrictions and infection control procedures. EOL nutrition conversations for residents with COVID-19 involved frequent updates to caregivers due to the rapid progression of the virus and addressed the unique nutritional challenges that came with infection. The results from this study can help develop resources for pandemic planning specific to nutrition. It also provides opportunity for greater dietitian involvement as they have not often been included in EOL nutrition care before or during the pandemic despite their expertise on the topic.

CHAPTER 6: GENERAL DISCUSSION

The objectives of this study were to examine the food and eating perspectives of HCPs of residents at EOL in Manitoba LTC homes to determine the best information to guide EOL conversations, what the most effective delivery methods are, and when this information would be the most beneficial. The study results are presented in the form of two manuscripts in chapters 4 and 5.

EOL care is typically defined as the care provided in the final months, weeks, or days of life (Hui et al., 2014). The dying trajectory of older adults is not predictable, making it difficult to define when a resident is at EOL and actively dying (Banerjee & Rewegan, 2016; Bern-Klug, 2009). Some residents die unexpectedly in their sleep while others may live with advanced disease for years (Bern-Klug, 2009). It can also be difficult to predict the dying phase of residents with frailty as it is characterized by a gradual decrease in function (Hall et al., 2021; Lynn, 2005). Based on the challenge of determining when a resident is nearing death, the term EOL was be used to describe the care provided to all residents from the time of admission until their death. In this context, not all residents are actively dying, but they are at EOL due to the expected decline in health while in LTC (Bern-Klug, 2009). EOL care takes a palliative approach, which supports open communication about EOL at any stage in the illness trajectory (Beacon, 2013; Kristjanson et al., 2003). At the beginning of each interview, this definition of EOL was read to participants (Appendix B). Throughout the interviews, when HCPs were discussing EOL they used it in the context of the final weeks or days of life when death is more imminent. In the literature on EOL care in LTC, many HCPs defined EOL as the period of time when death is imminent, the final stage of life (Froggatt & Payne, 2006; Wallace et al., 2017). It has not been until recent years (Kaasalainen et al., 2019, 2020) that a palliative approach in LTC that includes care from time of admission has been emphasized (Cloutier et al., 2021; Froggatt et al., 2020). Traditionally, palliative care has focused on cancer, but Kristjanson and colleagues (2003) stated that this approach can also be used for older adults with other life-limiting illnesses, such as neurogenerative disease.

The first objective was to examine the food and eating perspectives of HCPs of residents at EOL in Manitoba LTC homes to determine the best information to guide EOL conversations in normal conditions and during a pandemic. Based on the HCPs definition, at EOL (actively dying), they view food as something that is no longer needed and is rather provided as part of

comfort care, where food that is nostalgic or comforting to the resident is offered. A small number of HCPs believe that food is important in prolonging the life of the resident. Looking at current processes for EOL conversations, they are usually initiated by an interdisciplinary team that involved nurses and dietitians if available. HCPs self-rate their confidence in taking part in EOL nutrition conversations as high, stating that experience and informal training has led to this. Few LTC homes have formal policies or practices for EOL nutrition that they follow. Visitor restrictions, infection control procedures, and the uncertainty of the COVID-19 virus had a negative impact on EOL nutrition conversations. Visitor restrictions made it virtually impossible for caregivers to connect with their loved one in-person making it more difficult for them to understand the changes the resident was experiencing. HCPs had to provide more updates on their condition to fill this gap. EOL nutrition conversations were initiated later than usual, moving from on admission to after the resident's post-admission quarantine. Residents infected with COVID-19 experienced unique nutritional challenges, such as changes in appetite and swallowing issues. HCPs initiated conversations about nutrition as soon as residents tested positive as the progression of the virus was unpredictable.

The second objective was to determine when nutrition EOL information would be the most beneficial, and what are the most effective delivery methods once the resident is admitted into a LTC setting. As caregivers commonly believe that food will keep the resident alive longer, it is important that the consequences of feeding at EOL and the role of food (or lack of) is provided to caregivers. As food is seen as a way to show love, caregivers should be provided with alternative ways that they can show their love without providing food. The best time to initiate EOL nutrition conversations with caregivers is at the earliest opportunity, whether that be on admission or when the resident begins to experience a change in condition. It is important to introduce the topic early, even if it is not an in-depth conversation, as it prepares the caregiver for what is expected and ensures they are not overwhelmed when the resident is actively dying. HCPs stated that the most effective delivery method was the use of in-person conversations as it allowed for them to read the caregiver's body language to assess how much information is appropriate. These conversations can be supplemented with resources that caregivers can take home and read at their own pace, asking questions about the topic as needed. Overall, HCPs need to assess the caregiver's understanding of EOL and their beliefs to tailor the nutrition discussions to each individual case.

The three HCP disciplines (nurse, dietitian, and healthcare aide) were not analyzed separately, but one noted difference was that the belief that food is still important at EOL for prolonging life came from nursing. This presents an opportunity for further research to examine the EOL nutrition beliefs of the many disciplines working in LTC to tailor educational resources to each. In addition, it was also seen that the healthcare aide does not directly participate in EOL conversations with caregivers, but rather relay information on resident status to nurses. They expressed a desire to be more involved in conversations with caregivers, but are limited by their scope of practice.

A formal analysis of differences between the regional health authorities could not be carried out as only four participants were from one of the three health regions included other than the WRHA. Any noted differences are as follows: Prairie Mountain Health has their own resources on EOL that are provided to caregivers, whereas the one participant from Southern Health said that they use WRHA resources, which discusses EOL as actively dying. The participant from Interlake-Eastern had a very low EFT, therefore does not participate in EOL nutrition conversations substantially, but they also mentioned the use of WRHA resources.

Theory of Holistic Comfort

Comfort is a holistic outcome achieved when basic human needs for ease, relief, and transcendence are met in the context of physical, social, psychosocial, and environmental dimensions (Kolcaba, 1991, 1994). In this study, THC was applied in the context of social, psychospiritual, and physical dimensions. The environmental dimension of comfort was only discussed by one HCP, where they mentioned a resident had written down what they wanted their death to look like.

> …they [the resident] had written a detailed account of what they wanted their last days to look like…also what they wanted the scene of their death to look like- they wanted a certain kind of music, they wanted their family to be allowed in and allowed to hold their hand. (P971)

Nutrition has more opportunities to play a role in comfort through the environment. HCPs discussed care within the resident's room, but meals often occur in a larger dining setting. The dining room environment has an impact on resident experience by allowing for autonomy, independence, social interactions, and enjoyment of the meal (Hung et al., 2016).

HCPs provided social support to caregivers by ensuring their needs were met through frequent updates. For some residents, having family and friends around at EOL is important to them and brought them comfort. Allowing for these social interactions at EOL is another way that HCPs addressed comfort in the social dimension: "I think the interpersonal, like having family around, being connected with other people is very important at end of life." (P121)

Psychospiritual comfort was addressed through the meaning of food to the resident and their families. Each culture and/or religion have their own meanings of food, and HCPs worked with caregivers to understand what food means to them and how they can provide/have food present in a safe manner as well as teach them other ways to show their love. Providing care that aligns with the resident's beliefs and cultures is the aspect of EOL care that addresses the psychosocial dimension of comfort.

> Because I think that if, even with comfort care, if those don't align with the resident's culture or personal beliefs then you're really not meeting their desired goals of care which is what your aim as a professional is to do… (P971)
>
> I think in most cultures that's [food] how we express love and that's how we express affection and that's no different… food is a cornerstone of how you express your devotion both to your, to God and also your family members. (P315)

Finally, physical comfort involved symptom management. Having caregivers perform mouth care to relieve resident discomfort allows them to show love and care other than providing food at the EOL. Symptom management is a way to control pain such that emphasis can be placed on discussions of other aspects of EOL care: "…because if we can stay on top of pain control and anxiety and distress, the family is more likely to be calmer as well as the resident and then more rational discussion can happen…" (P505)

> We have with, like dry mouths and people starving or not being allowed food and fluid, if you have a good oral gels or fluid hydrator, that's like a gel that you apply to the lips to keep them comfortable and that gives the family often to do, they can apply it as often as they want and they provide that, and that gives them something they can do… (P971)

For the comfort of residents to be addressed, HCPs need to have conversations with residents and their caregivers to assess their social, psychospiritual, and physical needs so that they can be applied as part of EOL care. These conversations are an important part of ensuring resident's comfort at EOL.

Strengths

A strength of this study is the inclusion of dietitians as the majority of research on EOL nutrition only includes those providing direct care to the resident, such as nurses and physicians (Cagle et al., 2017; Firnhaber et al., 2020). From our study, dietitians indicated they want to be more involved, also seen in the literature (Pinto et al., 2016). Another strength is the use of survey-type questions paired with open-ended questions (mixed methods form), which allowed participants to provide reasoning for their responses.

Limitations

As with any study, limitations exist. Convenience sampling was used for participant recruitment and the data may not represent all HCP perspectives from all health disciplines in Manitoba LTC homes. There are other HCPs such as social workers, spiritual health workers, recreation workers, and physicians that take part in EOL conversations, but we were unable to recruit any. In addition, there were no participants from the Northern Health Region, therefore the finding may not be completely representative of provincial EOL nutrition practices. This data was collected over a 9-month timeframe where COVID-19 infections greatly impacted LTC and caused many outbreaks, hence difficulties in recruitment. LTC profit status and cultural affiliation associated with the participants were not collected, which did not allow for comparisons of their impact on EOL nutritional practices.

Implications of Findings

These results will contribute to the development of training and education programs for HCPs, allowing for better team involvement in EOL conversations. Constructive and timely conversations will engage and empower both the resident and/or caregiver in meeting residents' wishes around dying with dignity. The findings will also help inform pandemic planning by providing insight on the unique challenges that arise from visitor restrictions and infection control procedures. The nutritional issues that accompanied COVID-19 infections present the opportunity for dietitians to become more involved in EOL conversations.

Future Research

Research on EOL nutrition in LTC should include the perspectives of residents and their caregivers to examine how to best address their needs. It should also include a variety of HCP disciplines for a wider range of opinions. The EOL nutrition perceptions of the different disciplines should be examined separately to determine if there are differences in their knowledge and beliefs on the topic. HCPs should be purposively sampled to represent the various cultures and religions of LTC to assess if those characteristics affect EOL nutritional practices. It was found that the environmental dimension of comfort was only addressed in one interview, therefore further research is needed to see if food and nutrition can address this dimension through the dining experience. As this study focused on EOL in older adults in LTC, future research should examine EOL definitions and practices for younger adults in LTC with intellectual and developmental disabilities. Research on COVID-19 in LTC should gather perspectives Canada-wide on EOL nutritional conversations and processes as provincial experiences with the virus vary. Exploration of definitions of EOL and the palliative care approach is needed with HCPs in LTC.

Take-Away Points

Research objective 1: Examine the food and eating perspectives of HCPs of residents at the EOL in Manitoba LTC homes to determine the best information to guide EOL conversations in normal conditions and during a pandemic.

1. How do HCPs perceive food and eating at the end of life for older adults in LTC?
    - HCPs use the term EOL in the context of a resident that is actively dying
    - Most HCPs stated that at EOL, food is no longer provided to maintain nutritional status, but rather to provide comfort to the resident
    - Some HCPs believe that food is still important at EOL to prolong life
    - Nourishment was rated as the least important aspect of EOL care 87.5% of the time

2. What is the current process for delivering EOL nutrition conversations?
    - Very few LTC homes have formal policies or practices for EOL and if they are present, they do not include EOL nutrition

- Within the discussion of EOL, nutrition is brought in regularly, especially when a dietitian is involved
- Practical opportunities to partake in EOL conversations need to be integrated into HCP's education to increase their comfort with the topic
- To support EOL nutrition messages, caregivers need access to up-to-date educational materials, community organizations, and support of dietitians

3. What impact has COVID-19 had on EOL conversations in LTC homes?
    - Modifications had to be made to EOL conversations and processes due to visitor restrictions, such as virtual conversations and providing more information on resident status to the caregivers to bridge the gap.
    - New COVID-19 restrictions meant that HCPs had to make adaptations, which included pausing palliative care team meetings and working with other disciplines to gather health information about the resident and relay it to caregivers
    - Due to the rapid progression of the virus and eating challenges that accompanied infection, conversations about the care provided to residents with COVID-19 had to be modified to discuss the gastrointestinal issues that came with infection and predicting health trajectory

Research objective 2: Determine when nutrition EOL information would be the most beneficial, and what are the most effective delivery methods once the resident is admitted into a LTC setting.

4. What do EOL nutrition conversations in LTC currently look like?
    - Conversations on EOL nutrition include the discussion of feeding and swallowing changes along the dying trajectory, education on safe feeding, and discussing goal of care
    - EOL nutrition is discussed using an interdisciplinary team often with a nurse and dietitian
    - The ability of HCPs, especially dietitians, to take part in EOL nutrition conversations is limited by EFT

5. What EOL nutrition information is beneficial for caregivers to support decision-making?
    - HCPs stated that caregivers frequently believe that food will cure or prolong the life of the resident, therefore information that would be helpful include the consequences of feeding, disease and dying trajectories, and that food will not cure or prolong the life of the resident.
    - As caregivers have differing levels of knowledge on the topic of EOL nutrition, HCPs need to first assess caregiver expectations and knowledge

6. What are the most effective delivery methods for EOL nutrition information once the resident is admitted into an LTC setting?
    - In-person conversations are the best as they allow for the HCP to read the caregiver's body language and the caregiver is able to ask any questions they have
    - Other ways that EOL nutrition can be presented is through educational presentations and online resources that caregivers can read at their own pace, and virtually (over the phone or video-conferencing)

7. When should EOL nutrition information be discussed with caregivers?
    - On admission or when there is a change in intake or development of dysphagia were rated as the most appropriate times to initiate EOL nutrition conversations
    - Continuation of EOL nutrition conversations is dependent on the resident's condition as well as the level of understanding of caregivers

Summary

The results of this study demonstrate that HCPs in LTC navigate tensions at EOL through balancing comfort and nutritional needs of the resident, and bridge the nutritional divide by providing education to caregivers. The COVID-19 pandemic affected the way that EOL nutritional conversations were carried out due to visitor restrictions and the rapid progression of the virus.

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Appendix A: HCP Recruitment Poster

Healthcare Providers Needed for a Research Study

Navigating the Nutrition Information Landscape for Healthcare Providers of Residents in Long-Term Care Homes at the End of Life

We are looking for participants for a 30-45 minute audio-recorded telephone interview. Questions asked will be on the importance and perspectives on nutrition and end of life conversations of healthcare providers of older adults in Manitoba long-term care (LTC) homes.

The objectives of this study are:

1. Examine the food and eating perspectives of healthcare providers of residents at the end of life in LTC homes to determine the best information needed to guide end of life conversations in normal conditions and during a pandemic.

2. Determine when nutrition end of life information would be the most beneficial, and what are the most effective delivery methods once the resident is admitted to a LTC setting.

Participants need to:

1. Currently work in one or more LTC homes in Manitoba for at least the past two years
2. Take part in end of life discussions at the LTC you work in
3. Able to carry out conversations in English.

For more information, please contact the Research Coordinator Haley Pidborchynski at XXXXXXXXX or call Dr. Christina Lengyel and leave a detailed message at XXXXXXXX

Participants will be compensated for their time with a $25 Superstore e-gift card

University of Manitoba

This research has been approved by the Research Ethics Board 2 at the University of Manitoba. Any concerns about this project, contact Dr. Lengyel (XXXXXX) or the Human Ethics Coordinator (HEC) at (204) 474-7122.

Appendix B: HCP Interview Guide

Date/Time:_____ Participant Code:_____

Hello, may I speak with XXXXXX? Thank you.

This is Haley Pidborchynski, I am a research coordinator for Dr. Christina Lengyel at the University of Manitoba. We spoke on (DATE____) about your participation in this interview as a healthcare provider in long-term care. I would like to thank you for volunteering your time today. This research is funded by the Canadian Foundation for Dietetic Research.

Does this time still suit you for your 30-minute interview?

Yes: continue

No: reschedule

As you recall, this research is about the food and eating perspectives surrounding end of life care in long-term care homes. End of life care for residents in long-term-care describes the care provided to all residents from the time of admission until their death. It supports open communication regarding the wishes of the resident and caregivers about care and provides psychosocial and spiritual support. This study will enable us to provide nutrition and end of life information to long-term care homes for use in the development of policies, procedures, and educational training, and updated education materials about nutrition at end-of-life for substitute decision makers.

The purpose of this research is to examine current perspectives surrounding end-of-life nutrition conversations in long-term care (LTC) homes in Manitoba, and determine what information is needed to best guide these conversations.

Before we begin, there are a few things to remember:

- There are no right or wrong answers to any of the questions I will ask you. Please feel free to share your opinions and thoughts.

- This session will be audio recorded. Once transcripts of this interview are reviewed for accuracy, the audio recording will be destroyed. Transcripts will be destroyed once the information is aggregated and summarized into a report.
- You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence.

Do you have any questions before we begin?
You may want to have a pen and paper handy to jot down your thoughts or the question.

I will start the audio recording now. Let's begin with a few questions about yourself and your job.

Please state your name

1. Year of birth:
2. Sex:
3. Occupation:
4. What is your EFT?
5. Years working in LTC:
6. What health region do you work in?

Now I will ask open-ended questions about your experience with EOL nutrition conversations while working in a LTC home.

1. Please rank these items in order of importance, 1 being most important and 5 being least important for the care of residents at EOL:

   Comfort care

   Nourishment

   Symptom management

   Quality of life

   Care aligns with resident's beliefs/culture

   a. Could you provide your reasons for choosing xxxx as the most important one?
   b. Are there any other aspects that are important to consider for residents at EOL and their caregivers?

2. What role does food and eating play at EOL in LTC?
3. Tell me about EOL conversations you have already had with caregivers
    a. What topics were covered? Prompt: food and nutrition→expand if mentioned, ask if not mentioned
    b. In your opinion, which topics are the most important to cover?
4. Tell me what nutrition in a good death looks like, either what you believe it is or if you've seen a good death in a resident, kind of what the nutrition care looked like
5. How is EOL nutrition information currently presented to residents and their caregivers?
6. Are there any other ways EOL information could be presented to residents and their caregivers?
7. Under what circumstances should EOL conversations about nutrition and changes in the ability of a resident to eat or drink be initiated?
    a. Prompt: (i.e. sudden change in health status, general decline, nutrition changes such as dysphagia or weight loss)?
8. When should EOL conversations about nutrition and about the possibility of changes in resident's ability to eat or drink, be initiated? Rank in order of importance, 1 being most important and 5 being least important:

    On admission

    In a care conference

    When resident is actively dying

    Development of feeding and swallowing issues

    Changes in intake

    a. Could you provide your reasons for choosing xxxx as the most important one?
9. How frequent should EOL nutrition conversations occur?
10. Are there formal policies or practices in LTC for EOL that you follow?
        i. Yes/No
11. Are you part of a team that initiates EOL conversations with residents and caregivers?
    a. Yes/No
        i. If Yes, who is on this team? (position titles, not names)
        ii. If No, who initiates the conversations in your LTC home? (position title, not names)

12. How frequent is the discussion of nutrition in EOL conversations?
13. When are EOL (nutrition) conversations in LTC currently initiated? Please rate on a scale 1-5, 1 being too early, and 5 being too late
    a. Why do you feel this way?
14. How comfortable are you with initiating and continuing EOL conversations with caregivers and residents in LTC? Please rate on a scale 1-5, 1 being very comfortable and 5 being uncomfortable.
    a. Why do you feel this way?
15. What would allow you to feel more confident participating in EOL conversations?
    a. Are there any specific resources or training to help you do so?
16. What changes have you had to make with COVID-19 in relation to EOL conversations?
17. What changes have you had to make with COVID-19 in relation to the timing of and information provided in EOL nutrition conversations?

That is the end of my questions. Do you have any questions or additional comments?

Thank you so much for your time today. If in your consent form, you completed the section about receiving the summary of results, we will send that to you once the analysis is completed. If, at any time, you have questions or concerns, please contact Dr. Christina Lengyel using the contact information on your consent form.

Thank you very much for your time and for your commitment to improving the care of those living in long-term care.

Goodbye.

Appendix C: HCP Consent Form

Research Project Title: Navigating the Nutrition Information Landscape for Caregivers and Healthcare Providers of Residents in Long-Term Care Homes at the End of Life

Principal Investigator: Dr. Christina Lengyel

Sponsor: Canadian Foundation for Dietetic Research

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

End of life care for residents in long-term-care describes the care provided to all residents from the time of admission until their death. It supports open communication regarding the wishes of the resident and caregivers about care, and provides psychosocial and spiritual support. Problems arise when tough conversations regarding nutritional care goals and expectations do not occur or are untimely. COVID-19 has further impacted nutritional care of older adults in long-term care.

The objective of this study is to identify and understand the perspectives of caregivers and healthcare providers of residents in LTC with regards to nutrition and end of life conversations and practices in normal conditions and during a pandemic. This study will enable us to provide nutrition and end of life information to long-term care homes for use in the development of policies, procedures, and educational training, and updated education materials about nutrition at end-of-life for substitute decision makers.

Data collected from this research will be summarized and reported at conferences and published in peer-reviewed journals. You will have the opportunity to request a summary of this information

The study involves your voluntary participation.

- Once we receive this completed consent form, you will receive an email/phone call with a number of proposed dates and times for the follow-up interview.
- The 30-45 minute interview will be done over the phone. The telephone interview will be audio-recorded and verbatim transcripts will be created. Audio recordings will be destroyed once we review the transcripts for accuracy with the audio file; all research data will be destroyed once the research results are finalized.
- You will be compensated for your time with a $25 gift card to a grocery store which will be emailed to you after the interview is completed.

Your name and any identifying information will not be associated with your answers to the interview questions. All electronic data (i.e., audio files, interview transcripts, the interview schedule) for this study will be kept strictly confidential by Dr. Lengyel and her Research Coordinator by encrypting files, password protecting the one computer used in this research, and limiting access to that computer (only the researcher and the coordinator have access to the locked facility where research occurs). All physical data related to your responses (i.e., your printed consent form and one backup memory stick) will be kept in a locked cabinet in a research laboratory (a locked facility) until September 2026 or until data are published, whichever comes first. Your email will be deleted from our system when our email interactions are complete. You are reminded that you should retain a copy of this form for your own files.

As this research also considers the thoughts of caregivers and staff, we will analyze and ***may*** report information using the categories: “caregivers” and “health care providers”. We would do this to bring more meaning and context to the findings that we report.

Do not feel obliged to answer any questions for any reason. You may withdraw at any time without any consequences to you. Your anonymity and confidentiality will be protected by using codes in the transcripts; your name or location will not be used.

Risks associated with this study are no greater than in everyday life. A list of resources is provided at the end of this document. The results of this survey will be reported in aggregate and will not contain any individual identifiers. The report on the survey results will be potentially published in academic journals and presentations at conferences. No individual data will be reported. There will be no adverse consequence of choosing not to participate in this study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in this research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

If you choose to withdraw, all information you provided will be deleted and shredded as soon as possible. The gift card will still be sent to you afterwards. The process to withdraw is: contact Dr. Christina Lengyel by using any of the contact methods listed at the top-right corner of the first page of this consent form. The deadline for withdrawal is 24 hours after your interview.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research is approved by the Research Ethics Board at University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or

humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

An advantage to your participation in this research is that you will be at the forefront of research about a critical issue in long-term care and will provide insight into improving the care and quality of life for those in care. As well, you will have advance notification of a summarization of the research findings. If you request a summary of the study they will be sent to you via email and we will delete your email from our system after they are sent to you.

Please return the signed consent form (via email/mail) as soon as you can. We will not interview you until you have signed and emailed the completed consent form. If you have any questions about the consent form, please do not hesitate to contact Dr. Lengyel at christina.lengyel@umanitoba.ca

Please check one of the following statements before proceeding:

□ Yes, I agree to participate in this study

The interview session will be audio recorded. Please check the box below to agree with being audio recorded. If you do not agree to a recorded telephone interview, you may not participate in this interview.

□ Yes, I agree to have my telephone interview audio recorded
□ No, I do not want my telephone interview audio recorded

If yes, please fill out the information below.

_____

Participant's Signature Date

_____

Researcher and/or Delegate's Name Date

Should you need support at any time, here are some resources:

Health Links (204-788-8200 or toll-free at 1-888-315-9257)

Canadian Mental Health Association Winnipeg Phone Line (204-982-6100)

WRHA Mobile Crisis Service (24hrs: 204-940-1781).

Your gift card for participating in this study will be emailed to you in the form of an e-gift card. Please provide your email address below:

Email: _____

If you <u>do not have email</u>, please provide a mailing address below so your gift card can be mailed:

Name:_____

Street Address/ PO Box: _____

City: _____

Postal Code: _____

We expect that a summary of the results will be available by June 2022. For a copy of the study results please complete the following:

_____

Name (Please Print)

Preferred Email Address:

_____

E-mail Address (Please Print)

Appendix D: Study Timeline

	2021				2022			
	Apr/May	June/July	Aug/Sept	Oct-Dec	Jan/Feb	Mar/Apr	May/June	July/Aug
Revision to existing methods	✓							
Ethics amendments	✓	✓						
Participant recruitment		✓	✓	✓	✓	✓		
Data collection			✓	✓	✓	✓		
Data entry, coding, & content analysis					✓	✓	✓	
Writing						✓	✓	✓
Thesis submission to Advisory Committee								✓ (July)
Thesis defence								✓ (August)
Submit final thesis to Graduate Studies								✓ (August)

Appendix E: University of Manitoba Ethics Approval

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

RENEWAL APPROVAL

Effective: June 15, 2022 New Expiry: July 14, 2023

Principal Investigator: Christina O Lengyel
Protocol Number: HS23016 (J2020:036)
Protocol Title: *Navigating the Nutrition Information Landscape for Long Term Care Residents and their Decision Makers at the End of Life*

Andrea L Szwajcer, Chair, REB2

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

This approval is subject to the following conditions:

i. Any changes to this research must be approved by the Human Ethics Office before implementation.

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

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

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

Appendix F: Prairie Mountain Health Ethics Approval

PRAIRIE MOUNTAIN HEALTH
SANTÉ PRAIRIE MOUNTAIN

BRANDON

Brandon Regional Health Centre
Research Facilitator
Dr. Charles Penner
[redacted]

March 4, 2022

Christina O Lengyel
[redacted]

Dear Dr. Lengyel,

Re: *Navigating the Nutrition Information Landscape for Long Term Care Residents and their Decision Makers at the End of Life*

I am pleased to inform you that the research project, *Navigating the Nutrition Information Landscape for Long Term Care Residents and their Decision Makers at the End of Life* has been approved by the PMH Research Office. The approval is only for interviewing PMH staff and does not include caregivers or residents. You may conduct your research in PMH. If you have any questions about this approval please feel free to contact me a [redacted] Please submit a copy of your research findings at the stage of poster presentation or publication. This can be forwarded to the above e-mail.

Sincerely,

[redacted]

Charles Penner MD FRCPC
Research Facilitator PMH

cc: [redacted]

Appendix G: Southern Health Ethics Approval

SOUTHERN HEALTH-SANTÉ SUD
[redacted]
www.southernhealth.ca

February 24, 2022

Dr. Christina Lengyel
Primary Investigator
[redacted]

Haley Pidborchynski
Research Coordinator
[redacted]

Dear Dr Lengyel and Haley,

Thank you for your request to conduct research in Southern Health-Santé Sud. Your research proposal titled **Navigating the Nutrition Information Landscape for Long Term Care Residents and their Decision Makers at the End of Life** has been reviewed by Southern Health-Santé Sud.

After careful consideration it has been determined that your proposal meets the requirements to conduct research in Southern Health-Santé Sud until your Research Ethics Board (REB) approval expires July 14, 2022. Should you wish to continue your research please submit your renewed REB approval one month prior to expiry to [redacted]

Your Southern Health-Santé Sud contacts are:

NAME: [redacted]

The region is interested in reviewing the results of your research study and would appreciate a copy of the results sent to Kristine Hannah, Regional Lead – Quality, Patient Safety & Accreditation and Regional Ethics Chairperson at [redacted]

On behalf of Southern Health-Santé Sud, thank you for your interest in conducting research in the region. We wish you all the best in your study.

Kindest regards,

[redacted]

Kristine Hannah, Regional Ethics Chair
Regional Lead – Quality, Patient Safety & Accreditation

cc. [redacted]

Ensemble vers un avenir plus sain.
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Appendix H: Coding Table

Theme	Categories	Definition	Components (codes)
Contributions to quality of life	Considering both resident and caregiver wishes at EOL	Caregivers have differing levels of understanding on EOL, and this could impact the quality of death for the resident.	Resident wishes Comfort care Family expectations and knowledge Good death vs bad death Address caregiver needs Caregivers want resident to eat Differing levels
	Role of healthcare provider	HCPs provide education to caregivers on various EOL topics, as well as provide support to them. They also collaborate with other HCPs to ensure excellent care for the resident.	Dying process Not starving Consequences of feeding Food won't cure them Disease progression Goals of comfort Expectations Collaboration with other HCPs Support caregivers Limited by EFT (equivalent full time)
	Food has many meanings at EOL	Food plays many roles, from physical, to emotional, to no role at all. Maintaining nutritional status is not as important.	Nutrition not as important Symbolism of food Let go of food fight Resident wishes Comfort feeding Contradiction: food prolongs life
EOL processes	Delivery of EOL nutrition information	EOL nutrition information is provided to caregivers through various ways, including in-person conversations with an interdisciplinary team.	In-person conversations the best Email or phone Read body language Interdisciplinary team Depends on the needs of resident RD not always involved Region-specific resources
	EOL policies and practices	LTC homes vary in what informal/formal policies and practices guide EOL care	EOL protocol sheet Company-specific WRHA resources

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			Checklist Pathways No formal policies EOL toolkit for final days Informal practices Nursing has their own No EOL nutrition policy Practices when actively dying Policy would be too stringent Individualized
	When to initiate and continue conversations	EOL nutrition conversations are typically initiated when there is a change in condition or on admission. The continuation of EOL conversations is dependent on the condition of the resident and understanding of the caregivers.	Change in condition Diagnosis of dementia On admission Dependent on resident Feeding and swallowing issues Contradiction: Actively dying Not one pivotal moment Discussed as soon as possible Initiation issues Communication challenges Difficult families
	Contributors to HCP comfort and resources to develop confidence	Experience is the biggest contributor to HCP comfort with EOL nutrition conversations. Education and opportunities for experience need to be integrated into education and practicum programs.	Experience Reality of the work Empathy and passion for subject Support from team Informal training WRHA resources No RD training Professional development Academic institutions Case studies and discussions Mentoring new staff Sit-in on conversations Find own opportunities
Challenges during COVID-19	Modifications to EOL conversations and processes	EOL conversations and processes during COVID-19 required modification to accommodate new restrictions that impacted residents, caregivers, and HCPs.	Over the phone or virtually Visitor restriction Conversations are occurring less frequently Discuss after 2-week post-admission quarantine

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			Family less accepting of change Practices the same More communication with family Unable to develop relationship with family
	Adaptations of HCPs to new COVID-19 restrictions	HCPs experienced changes in their daily practice as duties shifted and extra infection control methods were required.	Less physical cues (weight) Time constraints Unable to meet with palliative care team to discuss practices Less RD involvement RD hands off role to nurse
	Conversations about healthcare provided for residents with COVID-19	Conversations about the care of residents with COVID-19 were much different than EOL conversations before the pandemic.	Difficult conversations Predicting health trajectory What to predict in COVID patients Severe cases warrant proactive approach Change in ability to tolerate diet New issues with COVID (blood sugar, swallowing) Respiratory distress